

Xmas Newsletter - Scleroderma Unit - Royal Free London



www.royalfree.nhs.uk/services/services-a-z/scleroderma/

From all of us

Christmas 2016

Dear Friends

May I wish you all a very Happy Christmas and a peaceful New Year. The past year has seen momentous changes in our society, and we can only hope that 2017 will bring joy and peace.

For me this past year had some special moments as I met or had contact with some of the patients I had looked after for many years. One was a wonderful accomplished young woman whom I first saw as a child, now doing very well in business. Another was a previous patient that I had helped to find the confidence to move jobs - not easy if you have scleroderma. The third is the proud mother of twins just starting at Oxford University - having had her twins despite diffuse disease. These patients made me very happy. I have seen so many developments that have helped patients, and I look forward to more in future.



Professor Dame Carol Black

Update from the Scleroderma Clinical Service

The clinical service continues to grow and develop within the Royal Free and also through our successful programme of outreach scleroderma clinics. In addition there are many opportunities to lecture and communicate with other professionals and examples over the past 12 months include presentations from the department at major meetings in Portugal, Amsterdam, EULAR Congress and the USA. There was even a recent lecture in Abu Dhabi on "how to set up a scleroderma service". It is excellent to see interest in scleroderma developing and the expertise of our centre being recognised.

After nearly 2 years of hard work the first National Scleroderma Treatment Guideline was fully published in 2016. This has been developed through the NICE accredited process on behalf of the BSR (British Society for Rheumatology) and BHPR and so has the potential to help standardise and advance treatment of scleroderma within NHS. The full guideline is freely available on-line to all healthcare professionals (see: www.rheumatology.org.uk/resources/guidelines). In addition we have developed within the UK Scleroderma Study Group network (UKSSG) more detailed specific guidance for important scleroderma complications such as scleroderma renal crisis – to improve treatment of these rare but severe complications of scleroderma.

It is not surprising that there are also many challenges developing and managing the clinical scleroderma service within the current climate of the NHS. We are pleased that overall the Trust received a "good" rating from CQC (Care Quality Commission) when it was inspected earlier in 2016 but there remain real challenges to achieve the financial and clinical targets that are important for long term health of the Trust. We are currently trying to streamline PITU treatments and improve efficiency of the unit that is raising some issues for the trust management and nursing infrastructure but we hope that this will eventually help our service to better meet clinical demands.

We are fortunate to continue to have visitors in the clinic from doctors training in scleroderma and over the past few months have had excellent colleagues from Germany, Italy, Portugal, Spain, Hong Kong and Turkey. These doctors add to our service and also help to develop scleroderma services in their own countries. In addition many undertake research projects and develop long term friendship and professional associations with the Royal Free and UCL.

Professor Chris Denton



Update from the Scleroderma Research Laboratory

From the laboratory - Biomedical science news

As we head towards Christmas our newsletter gives us a chance to up-date you on our research activities and events that have taken place over 2016. Our biomedical research remains very active and grows in several directions, with several grants awarded and new staff joining the group. Much of our work has been presented at meetings, conferences and symposia this year. We continue to make new and exciting discoveries about Raynaud's and Scleroderma as we move forward our research programme and learn more about the disease process. We have continued our studies into inflammation and autoimmunity and the cells and molecules involved in scleroderma and our research into blood vessel changes in Raynaud's and scleroderma pulmonary arterial hypertension, exploring the reason for altered tone and changes in blood flow. Many of our studies are collaborative, either within the Hospital, the UK or internationally spanning continents and the world. Examples are those with colleagues in London including Dr Jacques Behmoaras at Imperial College, Prof Claudia Kemper at King's College and Prof Rizgar Mageded at Queen Mary's University in London, as well as in Grenada, Spain (Prof Javier Martin), Cologne, Germany (Prof Thomas Krieg), Paris, France (Prof Luc Mouthon) and Lund, Sweden (Prof Roger Hesselstrand), and New England, USA with Professor Mike Whitfield). We have also been working on understanding scarring and fibrosis in scleroderma, and identified several new pathways that appear to play prominent roles in inflammatory-driven fibrosis. These exciting discoveries will allow us to take our research finding into pre-clinical models and help us develop new treatments ready for clinical trials. As you can see from the research highlights it has been a very exciting year.

Research funding.

We have been awarded several research grants over the last months. These include project grant support from the Rosetrees Trust and Royal Free Charity to Drs Ioannis Papaioannou and Markella Ponticos to study genetics and scarring in scleroderma, a three PhD studentships jointly with Prof Lucie Clapp at the UCL Institute for Cardiovascular Sciences and Dr Vidya Mohamed Ali funded by UCL and ADLi Doha. These students are studying important aspect of vascular biology relevant to Raynaud's and scleroderma. We have also attracted the interest of several industrial partners who have agreed to fund collaborative research into understanding the scleroderma disease process and to begin on the pathway to develop novel therapies. We are also extremely grateful to Scleroderma and Raynaud's UK for their continued support and for the research grants that we have been awarded this year to continue our collaborative studies into important aspects of the disease process. 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.

National and International events.

A lot of our work has been presented at prestigious national and international symposium including the British Society for Rheumatology, the American Thoracic Society, the Scleroderma world congress, and at a rare disease meeting in Recife, north eastern Brazil attended by Drs Voon Ong and Xu Shiwen. We organised the annual translational medicine workshop at the Royal college of Physicians, which has now been running annually for over a decade, and an Anglo-Brazilian workshop on cardiovascular disease. We are now planning the next scleroderma international workshop with colleagues, which will be held in the summer of 2017 in Pittsburgh USA. These events are an important way by which we raise our profile world-wide and that of scleroderma throughout the biomedical research community and allow us to receive critical positive-feedback on our research endeavours.

New staff and visitors.

Several new staff have joined the group. Three new PhD students Jerry Abu Hanna, Fatima Al-Khelaifi and Asmaa Raees, are undertaking their training in laboratory-based research. And we also have two new research staff who have joined us from Brunel University, Harry Chinque and Yassmin Sohrabi.



Professor David Abraham



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Scleroderma Specialist Nurses – Louise, Annalyn & Joseph

The specialist nurses remain busy with their nurse led clinics and supporting both inpatient, PITU and outpatient areas where we see you here.

We regularly attend outreach clinics where we come to you at your local hospital and offer support and education alongside the Consultants. We also continue to be involved in the departmental research and audit so we are always grateful to you for filling out various questionnaires in clinic and on the wards, it helps us understand how scleroderma affects you and your views.

The support group also remains popular with a large group attending in October, this is a quarterly event that anyone is welcome to attend for mutual support in a confidential environment.

We look forward to seeing you soon or speaking to you on the advice line.

Have a peaceful Christmas and all the best for 2017

Update from the Pulmonary Hypertension Service

As you may know, our Pulmonary Hypertension service looks after patients with Pulmonary Hypertension which is due to scleroderma as well as other causes. Over the last year we have welcomed Dr Dan Knight, Consultant Cardiologist who is a specialist in cardiac MRI. The new cardiac MRI scanner is a very welcome additional service, giving superb information about heart disease in a non invasive study. Dr Phil Marino, a respiratory specialist at St Thomas's hospital, is also doing frequent clinics at the Royal Free.

We have two new videos on the Pulmonary Hypertension pages of Royal Free website - <https://www.royalfree.nhs.uk/services/services-a-z/pulmonary-hypertension/>. You may also wish to see Holly's story on projectscleroderma.com.

We work hard to bring our clinics closer to the patients and we travel to Margate, Brighton, Portsmouth, Plymouth, Bath and Belfast to see patients with PH. We are also involved in clinical trials and research in pulmonary hypertension so continue to strive for excellence in all we do.

Microvascular Diagnostics – Dr Kevin Howell

It has been good to see many of you during 2016, not only in our clinics but also at the Scleroderma Family Day and SRUK Annual Conference, where I gave presentations about the work of Microvascular Diagnostics.

As in past years, it has been a busy 12 months supporting the scleroderma service with capillaroscopy and thermography, and also preparing research for publication. As I write, many of my colleagues are getting ready to travel to the annual American College of Rheumatology congress, which this year is in Washington DC. We are involved with three posters which will be exhibited in Washington on capillaroscopy and thermography:

- Firstly, the Royal Free has contributed to a study in collaboration with Prof. Herrick at the University of Manchester, looking at the reproducibility of nailfold capillaroscopy analysis.
- Secondly, some of you kindly assisted us with the VALIDS project last winter – a multi-centre study on the reproducibility of hand cold challenge in scleroderma patients. Our first results are now incorporated into a poster and look encouraging, with a journal article to follow in 2017.
- And lastly, Louise Parker and I have been undertaking a thorough audit of the primary Raynaud's clinic which runs at the Royal Free on Monday mornings. As expected, we have found that progression to diseases like scleroderma is extremely rare in this group of patients, and monitoring nailfold capillary status and blood tests is a reliable way to exclude secondary Raynaud's phenomenon on an ongoing basis. Louise will be in Washington with our poster which delivers this important message.

I wish everyone a Merry Christmas and a Happy New Year, and look forward to seeing you all in 2017!



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Clinical Trials News

As the year comes to an end and we say goodbye to 2016, we continue to see patients in the Institute of Immunity and Transplantation and this has gone smoothly. We continue to receive positive feedback from the patients. Lucinda and Charlotte have joined the team and Ivy, our trials co-ordinator had a baby girl over the summer.

We have a number of on-going and new interesting clinical trials in Scleroderma, the following are just a few :

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. This study is on-going.

Tocilizumab: We completed the phase 2 study a year ago and we are just about to start the phase 3 study. We will be approaching suitable patients for this study

Spin: The purpose of this study is to provide better patient-centred care to individuals living with chronic diseases. We are halfway through our recruitment and have positive feedbacks from the patients that this study is needed as a platform for them to express the daily functioning issues faced living with scleroderma.

Rise: This is a study of medication that has already been approved for use in CTEPH (thromboembolic PAH) PAH patients. We are actively recruiting for early diffused SSC patients, this maybe a new potential drug, in Scleroderma

Thank you to all those who continue to volunteer, we appreciate you giving up your time to take part in our trials. If you are interested in participating or for more information feel free to contact us on **0207 317 7544** or alternatively you can email us on rf.clinicaltrials@nhs.net .

The clinical Trials Team

Dermatology Clinical Trials

The Dermatology Connective Tissue Disease service is currently undertaking some very exciting research in localised scleroderma (also known as morphoea). We are trying to identify the underlying genetic abnormalities in skin affected by localised scleroderma / morphoea, and the related inflammatory and sclerotic skin signalling that these trigger, which then cause the skin changes to occur. If we can identify these key factors, the hope is to develop more targeted and specific treatments, which currently do not exist.

If you (or someone you know has localised scleroderma / morphoea) and are interested in finding out more and/or potentially taking part, please email us at rf.ctddermatology@nhs.net

Thank you!

Dr Amanda Saracino
Consultant Dermatologist



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Kim Fligelstone

Hello, I have had systemic sclerosis for 29 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 in different ways, I would love to hear from you if you want to talk.

If your ever on the ward and would like a gentle massage please let your nurse know and they will contact the complimentary therapy department, this is a voluntary service and donations are very welcome. If you would like to talk with someone who has experience of living with systemic sclerosis and has had a transplant please let me know and this can be arranged.

The next Royal Free scleroderma local group meeting will be on Friday the 3rd March 2pm to 4pm, if you have any thoughts about topics please let the specialist nurses know. The next World Systemic Sclerosis Congress will be in February 2018 in Bordeaux, more details next year.

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. Have a lovely Christmas and a Healthy and Peaceful New Year.

Scleroderma Family Day – Saturday 13 May 2017

The 2016 Family Day was a very good day - some of the talks are on the Royal Free website - www.royalfree.nhs.uk/services/services-a-z/scleroderma/scleroderma-family-day/.

I look forward to seeing you on 13th May 2017 - the provisional programme is on page 6 of this Newsletter. If you are unable to attend we try to put as many of the talks as possible up on the Royal Free website.

Newsletter

We hope you enjoy our Newsletter but if you prefer not to receive it please let me know and I will take you off the list.

Fundraising

Two friends of Sarah Lloyd are doing the RacetotheStones 100K run for scleroderma in July, which is excellent news – they will I think be fundraising via Just Giving. . There will be a JustGiving page set up OK Sarah Lloyd plus Nikki plus marathon runners.

Diane Mitchell Millar has written a memoir called Pub and proceeds are being donated scleroderma at The Royal Free. Please email Diane if you would like a copy dimillar08@gmail.com.

Raffle Tickets

Once again we have enclosed a book of raffle tickets – we have this year [by popular request] increased the price to £1/ticket [50pm for 20 years!] the cost of a book is still £5 but less stubs to complete. If you do not wish to buy raffle tickets please discard them, you do not need to return unused books.

If you have any questions about please do contact me at p.yeomans@nhs.net or by phone on 01273 672686 or 020 7794 0500 x 33471 on Mondays.

Pamela

Contact Numbers

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Nurses Scleroderma Nurses Help-line	020 7830 2326



Scleroderma Family Day – Saturday 13th May 2017

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	Dame Carol Black
10:15 – 10:45	Review of Research Progress	Prof Chris Denton Prof David Abraham
10:45 - 11:10	Lessons from Sjogren’s syndrome ‘dry eyes and dry mouth’ in scleroderma	Dr Elizabeth Price
11:10 – 11:30	Factor XIII trial and other studies	Dr Anna Gill
11:30 – 11:50	Having a stem cell transplant – pt & Dr perspective	CD & Transplant Team
11:50 – 12:10	Psychological aspects of chronic immunological disease	Dr Mari Campbell Clinical Psychologist, RFH
12:10 – 14:00	Lunch break— discussion groups – see below	
14:00 - 14:30	Personalised medicine approaches to scleroderma	Dr Corrado Campochiaro
14:30 - 15:30	International Speaker – An Australian perspective	TBC
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/Annalyn Nunag
Thermography	Dr Kevin Howell

