



From all of us

www.royalfree.nhs.uk/services/services-a-z/scleroderma/
Christmas 2019

Dear Friends

A joyous Christmas to you all.

Another year has flown by. Tonight is special for me I will have dinner with a young woman I looked after from when she was a child I still remember her coming to my scleroderma clinic . Now she is an accomplished woman, but she has keep in touch over all these years. I still feel very strong links to Scleroderma and was delighted to open the International Scleroderma workshop in Cambridge in July. So much is happening in the field with so many more researchers trying to understand the disease and every aspect of treatment.

I have now finished my principalship of Newnham College but am still enjoying my work for the Government and have the privilege to Chair the British Library. I hope 2020 is a joyous one.

Happy New Year



Dame Carol Black

News from the Scleroderma Clinic Professor Chris Denton

It has been another busy and exciting year in the scleroderma clinic, with continuing real progress towards to developing new treatments. I would highlight the excitement that nintedanib, a drug already used for cancer and other forms of lung fibrosis, has become first approved therapy (in USA so far, hopefully the UK and Europe well soon follow) for lung fibrosis in scleroderma. In addition, several of the recently reported clinical trials of biological drugs such as tocilizumab and abatacept and romilkimab have each shown potential benefit for skin fibrosis, prevention of new lung fibrosis and improvement in hand function. These three antibody-based drugs each target very specific proteins implicated in the progression of systemic sclerosis. Although it is possible that not all of these positive findings will be directly applicable to the clinic, they provide strong encouragement for all patients and doctors involved in the trials. Positive effects in different subgroups of patients will lead to better understanding of the cause and mechanisms of scleroderma and also bring new treatments closer to reality. One of the main goals currently is to try and achieve the treatment benefit of intensive approaches such as stem cell transplantation but to have this in a safer and more acceptable form using more specific combinations of drugs.

We have been fortunate to have excellent clinical fellows to help us and very general support from individual donors that we very much acknowledge. Some of our talented clinical research team will present their work at the **25th Anniversary Family Day** on Saturday 02 May. As well as dealing with life threatening complications in the heart and lungs we are also now bringing new focus onto the bowel in scleroderma, that is consistently highlighted as one of the biggest unmet needs, and we will use this as an opportunity to look back at progress and achievements over the last quarter century. We very much hope that as many of our friends, patients and their families will be able to join this landmark occasion.





Laboratory and Research News

David Abraham & Scleroderma Research Colleagues

2019 in the laboratory

It has been a very exciting and busy year in the research group with a number of on-going studies into Scleroderma and Raynaud's. A number of new projects have begun, and several existing projects have been successful. These studies have enabled us to present our work at a number of key meetings, conferences and symposia both nationally and internationally. For example, our work has been presented at the British Society for Rheumatology, EULAR – the European league against rheumatism and recently at the American College of Rheumatology. At these events, our work has been well received. We have published many of our studies in associated scientific journals. A number of new staff have also joined the group - see below - and we have had a number of grant applications funded. This research support is vital to us, as it underpins the research studies we undertake.

Research progress

Our research studies into inflammation, blood vessel biology and fibrosis that are characteristic of Raynaud's and scleroderma continues to progress well. We have expanded into new areas and avenues of investigation and harness the expertise of colleagues and collaborators. Themes of collaborative work encompass studying blood vessel function in order to explore scleroderma vascular disease including peripheral vascular disease and arterial hypertension. These studies are in collaboration with Prof Lucie Clapp and Mrs Jerry Abu-Hanna at the Institute for Cardiovascular Sciences.

We are also focussing on skin disease in scleroderma and the role of dermal fibroblast metabolism in causing scarring and fibrosis. This research is led by Dr Xu Shiwen and in collaboration with Dr Jan-Willem Taanman in UCL neuroscience.

Dr Richard Stratton has been leading on studies exploring the role immune-regulators such as cytokines, chemokines and modulators of macrophage function of in controlling fibrosis. These studies are part of our translational programme towards clinical trials.

Other areas we are actively studying are the genetics of scleroderma (Drs Markella Ponticos, Carmen Fonseca, Dan Kelberman and Ms Venessa Acquaah. Dr Voon Ong has been pioneering our work on the immune system in scleroderma and the role of B cells, T cells and complement in early phases of the inflammatory disease process. These studies are truly international and involve collaborations with Prof Claudia Kemper from the US, Prof Bent Deleuran for Denmark and Profs Shahram Kordashi and Rizgar Mageed in the UK.

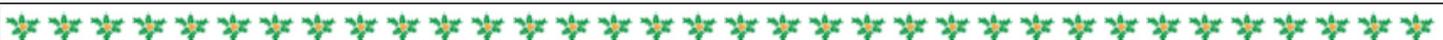
These studies are essential for us to deepen our understanding of Raynaud's and Scleroderma and to develop effective therapies. Dr Kristina Clark and Prof Denton have also just initiated another new area of research study. This exciting research will concentrate on a novel approach to study fibrosis in scleroderma and is likely to have a transformative effect on our understanding of the disease process.

New staff, collaborations and funding

A number of new staff have joined the group over the last year. These include three new PhD students Vanessa Acquaah, Hamyan AL-Obaidy and Nada Mohammed-Ali. Noshin Hussain and Usha Rai (both from Brunel University) have also joined the group to work with Korsia Khan and Bahja Ahmed Abdi looking at biomarkers in scleroderma and developing new assays to assess scarring and ageing in scleroderma.

Our collaboration with China continues with exchanges of staff between Xi'an and the Royal Free. Currently Ms Huan Liu is visiting from China and Dr Xu Shiwen has recently visited Xi'an Jiaotong University in China to continue the collaboration.

We have been successful with a number of research grants recently. We have been awarded grants from Royal Free Charity, the NIHR/Biomedical Research Centre (UCL), the Newton Fund and from industrial partners. Dr Kristina Clark was recently awarded an MRC fellowship and Ms Vanessa Acquaah was awarded a British Heart Foundation PhD studentship. This portfolio of funding supports the biomedical research studies into Raynaud's and scleroderma as well as investigating novel approaches to treatment.



Microvascular Diagnostics – Dr Kevin Howell

It's been another busy year for the lab, with around 800 patient visits for capillaroscopy and thermography tests.

During 2019, I have continued to travel across the UK to support a number of projects...

Back in March, I was part of the teaching faculty on the 3rd British Society of Rheumatology Capillaroscopy Course at Salford Royal Hospital in Manchester. This is now a well-established resource for training rheumatologists about the importance of nailfold capillaroscopy in screening for scleroderma.

Back in London, in the second half of the year I have also given presentations on the work done in the Microvascular lab to Kings's College and Great Ormond Street Hospitals. Here at the Royal Free, I also ran a short teaching session in the autumn as part of the scleroderma module of the BSR Rare Diseases Fellowship.

These presentations are all important opportunities to ensure that the microvascular techniques we offer are widely known about across the rheumatology community.

Looking further afield I was in Poland twice this year; firstly at a thermal imaging Congress in Zakopane in April, and then in August in Wrocław, inspecting the conference facilities at the city's University of Environmental and Life Sciences. This will be the venue for the next congress of the European Association of Thermology in September 2021, and as EAT President I am keen to ensure we have plans in place in good time.

My final travel commitment, at around the time you read this, will be to Kuwait to bring capillaroscopy education for the first time to the middle east.

From the Institute of Immunity and Transplantation, I wish you all a Merry Christmas and a Happy New Year!

Kevin

Kim Fligelstone

Hello, my name is Kim, I have had systemic scleroderma for 32 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.

The 6th Scleroderma World Patient Congress, takes place in Prague from March 5-7, 2020, & will be live-streamed for access by all those who cannot attend in person. Registration for the patient congress is subsidised to a low cost, and includes lunch on Friday.

The patient congress opens at 9 am on Friday 6 March and concludes at 1 pm on Saturday 7 March, with opening lectures for both patients and doctors together on Thursday 5 at 17.30 pm, followed by a welcome reception at 20.00. As part of the patient congress, there will be smaller sessions for men only, and for women only, to discuss sexual and other intimate concerns; and also sessions for the parents of children with scleroderma, and for young people who are dealing with the disease.

A patient dinner is also being organised for Friday evening, places are limited so please book when you register. Congress Registration is open now at the following link, and those attending can also book hotels through the organising agency, AIM, at the same link. <https://web.aimgroupinternational.com/2020/patientcongress/>

If you are 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.

The next Royal Free Raynaud's & scleroderma local group meeting will be on Friday the 20th March, 2020 at 2pm in the Rheumatology Library, opposite the main lifts on the Lower Ground Floor. The guest speaker is Mari Campbell Consultant Clinical Psychologist at the RF.

The Royal Free Support Hub offers support and information including Welfare and benefits advice, Talks and workshops and Activities to people affected by long-term health conditions. For all enquiries or to make an appointment Tel: 0207 7794 0500 ext 39963 Email: rf.royalfreesupporthub@nhs.net

If you use this service please let me know how you get on.

My contact details: 020 7794 0500 ext. 35131 or 0207 794 0432. 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.

Lots of Love, **Kim**



Clinical Trials News

This year has been an exciting and fast paced year for the clinical trials team. We have welcomed some new team members, including Dr Philip Yee, Dr Megan Galloway, Stella O'Connor and Kanta Mahay. We have also received some positive results for recent clinical trials that the department has been involved in, and this helps to motivate us all to continue our work in research. For example, a recent Phase III study showed that the drug nintedanib slows the loss of pulmonary function in people living with SSc associated ILD. The company is now hoping to get licensing approval.

As we get ready for the New Year, we are excited to introduce some new studies that will open for recruitment in 2020:

ASRAP: The aim of this study is to further refine the development of a new Assessment of Scleroderma associated Raynaud's Phenomenon (ASRAP) questionnaire, which has been designed to assess Scleroderma-Raynaud's Phenomenon.

Beyond DETECT: To explore the application of the DETECT clinical tool for early diagnosis of Pulmonary Hypertension in a real life SSc population.

We also have a number of studies that are continuing to recruit, including:

Predss: Determine the efficacy of moderate dose prednisolone, compared with placebo treatment, in reducing pain and disability, and improving skin score (reducing skin thickening) in patients with early diffuse cutaneous systemic sclerosis (dcSSc).

Sys-Stem: We are collaborating with Prof Butler on a trial of fat transfer to treat mouth fibrosis in Systemic Sclerosis. This study is currently recruiting.

Strike: This study focusses on the disease progression of patients diagnosed with Scleroderma. The aim is to collect data to enable us to better predict who will be likely to undergo disease progression in the future.

We would like to thank all of you who volunteer your time to take part in our trials and research studies. If you are interested in participating or would like more information, feel free to contact us on 0207 317 7544 or alternatively you can email us on rf.clinicaltrials@nhs.net

Scleroderma Specialist Nurses update

As we get ready for the New Year the scleroderma specialist nurses are busy with the rest of team supporting the clinics, PITU (our day unit), seeing our inpatients and attending outreach clinics where possible. Winter time is especially busy of course but that means we get to see more of you!

The digital ulcer clinic is well used in the colder months too, if you have any issues with ulcers and would like to see us in this dedicated nurse-led clinic please get in touch.

Do let us know if you have any queries or concerns via our advice line and we will do our best to help or direct you to other resources.

Just a reminder Nurse advice line:

For clinical or medication queries 0207 830 2623

Scleroderma coordinator - appointments, lung function and echo tests - 0207 794 0500 Ext 32909

We hope you have a lovely Christmas and best wishes for 2020.



Louise and Joseph



Norlan Dubissette – Scleroderma Patient Navigator

Hello everyone

Some of you may have spoken to me over the phone. My Name is Norlan the patient pathway Navigator for Scleroderma.

I would like to remind everyone that I take care of your annual appointment which often includes having Echocardiograms and ECGs schedule to help fit in with this appointment. If you need to reschedule your annual appointment, please ensure you contact me three months before your appointment, so I can reschedule your whole day for you.

I will ensure that we make your Scleroderma visit as stress free as possible.

I would like to wish everyone a happy Christmas and a prosperous New Year.

All the best,

Norlan Dubissette
020 7794 0500 ext 32909

Scleroderma Family Day – Saturday 02 May 2020

This will be our 25th Family Day – I cannot quite believe I have done them all! The draft programme is overleaf, it may change slightly on the day but not by much. Do come and join us, it would be lovely to see you.

Raffle Tickets

Please find enclosed a book of raffle tickets – monies raised from the raffle are enormously helpful and often funds laboratory equipment. If you do not wish to buy them please just discard them, there is no need to return them.

Fundraising

Many people have kindly raised money for the research unit in the past 12 months, from coffee mornings to running marathons - we are extremely grateful for their support, as it makes an enormous difference.

Newsletter

We hope you enjoy the Newsletter, should at any time you wish to stop receiving this please let me know and I will take your name off the mailing list. If you have any questions about any of the above please do contact me.

Pamela

01273 672686 – p.yeomans@nhs.net



Contact Numbers

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Scleroderma Nurses Help-line	0207 830 2623
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Kevin Howell	020 7794 0500 x 22516
Pulmonary Hypertension Nurses	020 7472 6354
Kim Fligelstone	020 7794 0500 ext 35131/020 7794 0432
Millie Williams	020 7794 0432
Pamela Yeomans	01273 672686 [Monday 020 8016 8406]





Scleroderma Family Day – Saturday 02 May 2020

25th Anniversary Meeting

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 – 10:20	Welcome	Dame Carol Black Profs Chris Denton & David Abraham
10:20-10:40	What is a Biopsy?	Dr Kristina Clark
10:40-11:05	Dental aspects of Scleroderma	Prof Stephen Porter
11:05-11:25	Gastrointestinal problems – shedding new light on old problems	Dr Fiza Ahmed
11:25-11:50	Pulmonary hypertension and the heart	Dr Gerry Coghlan
11:50-12:15	Scleroderma cohort studies - "Learning from our patients"	Dr Francesco del Galdo
12:15-14:15	Lunch break – see below	
14:15-14:45	25 years of progress - from "black box" to "positive trials"	Prof Chris Denton
14:45-15:15	International Speaker – Scleroderma Management in Netherlands	Dr Madelon Vonk
15:30	Raffle	

Lunchtime Discussions Groups / Demonstrations include

Clinical Trials	Rachel Ochiel and team
National Institute of Health Research	Christine Menzies
Drug information/monitoring	Jay Pang
Massage	Mr Keith Hunt, Complementary Therapies
Pulmonary Hypertension Education/nursing	Sally Reddecliffe/Adele Dawson
Rheumatology Laboratory	Research Laboratory Staff
Scleroderma Education/Nursing	Louise Parker/Joseph Cainap
Thermography	Dr Kevin Howell
Sjögren's Syndrome	British Sjögren's Syndrome Assoc

