

🔔 Xmas Newsletter - Scleroderma Unit - Royal Free London 🔔



From all of us

www.royalfree.nhs.uk/services/services-a-z/scleroderma/
Christmas 2020

Dear Friends

I know this has been a very challenging year for you all. The pandemic swept through the world causing havoc and loss. I am sure that patients with Raynaud's and Scleroderma will have felt vulnerable. So my greatest Christmas wish is that you are safe and COVID free. I know that Professor Denton and his team at the Royal Free will have done everything they could to keep in touch and provide support. This year I owe the Royal Free a great deal. My husband was in the hospital with COVID. It was a very worrying time but he received great care and came home after 11 days. I hope to 'see' many of you on line in the early summer when we do a virtual Family Day. Till then my warmest wishes for Christmas and the New Year.



Dame Carol Black

News from the Scleroderma Clinic Professor Chris Denton

When the last newsletter was written none of us could have imagined what would happen over the subsequent few months and the profound effect events linked to a new coronavirus would have on all aspects of our daily life. We have witnessed a catastrophic effect on UK and global health, as well as the economy. The scleroderma clinical service has had to adapt and adjust. Initially our concern was to maintain patient safety and ensure that scleroderma patients on immune suppression, or with serious heart or lung complications, were protected from risk. The government shielding programme helped achieve this and fortunately relatively few of our scleroderma patients have had confirmed covid-19. More importantly, as we learned more about this new disease it became apparent that scleroderma patients in general do not appear more susceptible to Covid nor affected necessarily in a more severe way. This is reassuring but scleroderma patients should still try to minimise risk and observe the recommended precautions. It remains a potentially lethal infection for those that develop the most severe form of Covid-19, as we are all well aware from the daily government updates.

I sincerely hope that the pandemic will come under better control in 2021. At the peak of the first wave our clinics were cancelled and PITU became an ICU for Covid-19 patients. All of the junior doctors and many of the senior nursing and medical staff joined the rapidly deployed "covid rota" to help treat the phenomenal number of cases that were admitted to the Royal Free and Barnet Hospitals. We are now establishing a "new normal" but it remains challenging. We are developing and expanding our service and most outpatient appointments are by video-link at present. However, we are still available for face to face consultations when necessary and expect that to increase next year. We have an excellent team including visiting clinical fellows from Netherlands, Portugal and Kuwait. The clinic and PITU are all now "Covid secure" and we are gradually increasing the number of test slots to co-ordinate with clinic visits and we encourage you to attend all virtual or on-site appointments. The scleroderma service will never be quite the same after such a tumultuous year but I am very confident that it will emerge stronger, more resilient and able to capitalise on medical advances including any new therapies emerging from ongoing clinical trials.

Finally, I would like to wish you all a Happy Christmas and emphasise that Family Day 2021 may be "virtual" but we do not expect it to be diminished. You will hear about some of the ongoing research and how clinical trials are starting to show which drugs may work in scleroderma and offer new hope for patients.



Research and Laboratory News

David Abraham, Korsa Khan & Scleroderma Research Staff

It has been a very challenging year in the research group where we have tried to minimise the impact of the Covid-19 pandemic on our laboratory work and research investigations.

We were asked to assist in the national interest for Covid-19 response to provide some diagnostic equipment during the pandemic. All the staff have responded tremendously by reorganising their working schedules, planning experiments and working effectively and remotely when needed.

The laboratory was partly closed for a brief period earlier in the year, but now with Covid-19 health and safety measures in place we are back up-and-running almost at full capacity.

Therefore there has only been a short delay the progress of our on-going research studies into Scleroderma and Raynaud's. Some new projects have begun, and several existing projects have progressed and we are now seeing some successes. Our work has also been presented at a number of key meetings. Due to the pandemic, many of the symposia and conferences met this challenge but organising Webinars - meeting hosted on via the internet. Both national and international symposia have been organised this way and we also run or annual workshop usually held at the Royal College of Physician's as an on-line webinar. Over 300 participants joined our workshop which as a record. Our work has been well received at these on-line events and we have had lots of feed-back and useful discussions. We have also managed to submit and publish some of our studies in associated scientific journals. A number of new staff have also joined the group and we have had a number of grant applications submitted and funded. This research support is essential to us, as it underpins all the research studies we undertake.

Progress in Research

Our research studies into Raynaud's and scleroderma continues to progress very well. To highlight a couple of studies; Dr Voon Ong is leading a project to investigate immune cell sub-sets in scleroderma. These studies will explore in more detail the cells in the blood which make the autoantibodies. Prof Markella Ponticos is overseeing a project studying the genes and proteins involved in the lung complications (fibrosis and hypertension) to discover new biomarkers and therapeutic targets. We have expanded into new areas of investigation and harness the expertise of colleagues and collaborators. The areas of our collaborative work include studying inflammation, blood vessel biology and fibrosis. To mention a few key collaborations including studies of vascular disease covering peripheral vascular disease and arterial hypertension (Prof Clapp, Dr Abu-Hanna and Calver Pang). The role if fibroblast sub-populations on skin disease in scleroderma in causing scarring and fibrosis (Dr Kristina Clark and Prof Chris Buckley). Research led by Emma Wei and in collaboration with Drs Voon Ong and Xu Shiwen are exploring the role immune-regulators such as cytokines and chemokines in controlling fibrosis. These studies are part of our translational programme towards clinical trials. Other areas we are actively studying are the role of macrophages and matrix cross-linking in tissue scarring (Prof Richard Stratton) and the genetics of scleroderma disease sub-sets (Drs Carmen Fonseca, Dan Kelberman, Otto Georg and Vanessa Acquaah). Dr Voon Ong has been also been leading work on the immune system in scleroderma with Prof Kemper/USA, Prof Deleuran/Denmark and Prof Kordashi/UK. These studies deepen our understanding of Raynaud's and Scleroderma and the develop effective biomarkers for disease management and eventually new and innovative therapies. Overall very exciting areas of research.

Looking to the Future – New Staff, collaborations and Funding

A number of new staff have joined the group over the last year. These include two new PhD students Ping Kang and Claire Beesley. Two new research assistants have joined us from Brunel University, Sanaah Amin and Maahia Choudhury to work with Korsa 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, and we will be hosting a visit from Dr Feng'e Zhang from Xi'an Jiaotong University in the new year. We will also host an Erasmus visiting scientist from Greece Dr Evangelina Christoforidi. Also one of our PhD students, Dafni Gyftaki is embarking upon an internship in pharma looking at fibrosis markers. We have been awarded grants from Royal Free Charity, the Newton Fund and from industrial partners. This portfolio of funding supports the biomedical research studies into Raynaud's and scleroderma as well as investigating novel approaches to treatment.



Microvascular Lab Update – Dr Kevin Howell

In keeping with the experience of everyone else, 2020 has not been the year that we anticipated for the Microvascular service...

Our diagnostic services closed at the end of March, and I was seconded to the Royal Free's Medical Electronics department in an equipment management role for a period of about six weeks. We were eventually able to begin limited capillaroscopy and thermography measurements again in August. This is far from a return to "normal," since we must limit patient numbers within the Institute of Immunity and Transplantation during the ongoing pandemic. So, for the foreseeable future there will unfortunately be extended waiting times for Microvascular appointments as we clear the backlog of cancelled tests and delayed referrals. We will do our best to get to everyone as soon as possible and ensure results are reported to each patient's consultant. If you have any enquiries about outstanding appointments, please do contact me. The lab now has a number for receiving text message enquiries, which has proved to be a convenient means of communication for both lab and patients: 07380 316623.

On a brighter note, we are continuing to contribute to UK microvascular research, and will be one of six European centres participating in a study next year which will test how well thermography can measure improvements in hand rewarming after treatment. Hopefully restrictions on our daily lives will be much less onerous by then, and the study can proceed at pace.

I would like to thank all of you for your patience in your dealings with the Microvascular lab this year, and wish you all a Merry Christmas and a Happy New Year. Let's hope 2021 is much more straightforward!

Clinic Trials News

As the year comes to an end and we say goodbye to 2020, we continue to see patients in the Institute of Immunity and Transplantation and this has gone smoothly. This year has been a rollercoaster to say the least, due to COVID-19, we went from a team of 14+ to 7, with staff redeployed, shielding, stuck overseas, and unwell with Covid symptoms. We are now back to full strength in our team, and are adapting our clinics to ensure they are Covid-safe.

Throughout the pandemic, we have continued to receive positive feedback from the patients. We have had new staff members join the team in 2020, including Tung Le (laboratory assistant), Sandra Lopez (admin assistant), and Dr Ben Coumbe (clinical research fellow).

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

Scleroderma Trials:

Galapagos: This is a phase 2, proof of concept study, which recently published results from its interim analysis that showed the study reached its primary endpoint with study drug Ziritaxestat. This is exciting news and we hope that the study progresses to phase 3.

IGPRO20 : This study is being carried out to see if IgPro20 is tolerated when administered to adult patients with systemic sclerosis that have skin involvement extending beyond elbows and knees. This form of systemic sclerosis is called diffuse cutaneous systemic sclerosis (dcSSc). The study will involve 16 weeks of treatment with IgPro20 (subcut Ig) compared to 16 weeks of treatment with IgPro10 (IVIg).

PRedSS: This study was initially a started off as 'double-blind' trial, meaning so neither you nor your doctor will know which treatment group you are in. Due to the COVID-19 pandemic the study was re-designed from double-blind to become an open-label trial, where both patient and doctor are aware of treatment allocation. In this case either Prednisolone no trial treatment (both groups continue to receive standard of care medication). Study visits have also been amended to allow for remote visits. Study duration is 6 months.

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.



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Scleroderma Specialist Nurses Update

It has certainly been an eventful year for all of us so far. The service has dealt incredibly well with the stresses of COVID and we have been in touch with many of you during this time.

Louise was redeployed for half her hours to ICU during March, April and May. Joseph and Louise, supported by our fantastic administrative colleagues Ade and Norlan, were handling double the amount of advice line calls and email contact from patients, GPs and other hospitals also during this time and throughout the summer.

We are slowly getting outpatient clinic activity up and running again which is a relief and we were delighted that PITU was able to re-open in late summer for our day infusion patients who needed their Iloprost and IVIG amongst other treatments.

We hope you keep well and stay safe. Wishing you a peaceful Christmas and all the very best for 2021.

Louise and Joseph

Kim Fligelstone

Hello, what an extraordinary and for some devastating 9 or so months (at the time of writing) that we have been living through. I know video and telephone appointments are challenging but hopefully by the time you read this some of the teething problems will be ironed out and I'd like to thank everyone reading this for your understanding and patience during all this. If you are experiencing a deterioration please contact your GP or if your not able to access them call the specialist nurses or a member of the medical team. Obviously if it's an emergency contact 999 or 111. At the time of writing we are going into another lockdown please see up to date government advice <https://www.gov.uk/government/publications/guidance-on-shielding-and..> & please take extra care and use common sense, better to wait/let someone pass you than compete for the same space whether it's on the pavement or on public transport.

Throughout the past months Dr Lesley Saketkoo's weekly exercise and mindfulness sessions on Zoom, have been helpful for some, they are suitable for everyone. Dr Saketkoo is Zooming from New Orleans early evening on a Friday and or Sat evening (UK time) contact me for the link. SRUK have organized some excellent sessions on living through the pandemic - check out SRUK's website <https://www.sruk.co.uk/> for information on anything to do with scleroderma & Raynaud's and the new Keep in touch Support Service and existing helpline. FESCA also have useful information and guidance regarding COVID 19 and much more <https://fesca-scleroderma.eu/>

It's now an unbelievable 33 years since I was diagnosed with scleroderma! I'm generally available on Wednesdays for phone calls, I must emphasize I am not a counselor, just 33 years of experience of living with the disease, although as you are probably well aware we are all affected in different ways, I would love to hear from you if you want to talk. For the time being call on the number below or email me, I check my emails fairly regularly even when I'm not at work if you let me know your contact details I can call you back.

Dr Cate Orteu, consultant dermatologist is hoping to set up a support group dedicated for people with morphea/localised scleroderma. If anyone is interested please contact me.

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.

Contact details: 020 7794 0432. You can email me at kim.fligelstone@nhs.net Leave a message with Millie or on the answerphone and I'll get back to you asap but please know that I'm only coming in one day a week, you can also try 0207 794 0500 ext 35131 but you can't leave a message.

I hope that Christmas & New Year will be the best you can have under the circumstances and really look forward to seeing some of you when we are able to meet up again, in the meantime we are hoping to organise a virtual Local Group meeting in the New Year. Take good care of yourselves.

Lots of Love Kim XXXX





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Norlan Dubissette – Scleroderma Patient Navigator

Dear Patients/Family,

I would just like to thank you all for being so patient and supportive through this difficult time. Hope we have a better 2021, so we can get on with our lives.

Wishing you a healthy and prosperous new year.

Norlan (Scleroderma Navigator)

Scleroderma Family Day – Saturday 22 May 2021

We were so sorry not to have been able to hold our 25th Anniversary Family Day in 2020 but we do plan to hold it in 2021 – sadly the only way we can do this is to have it as a virtual meeting. We will post the Zoom link for the meeting via the Royal Free website nearer the time – please go to the following link access the Zoom login details

<https://www.royalfree.nhs.uk/services/services-a-z/scleroderma/scleroderma-family-day/>

Raffle Tickets

We are not enclosing raffle tickets this year as we will be using the 2020 raffle tickets purchased for the 2021 raffle, which will be drawn at the Virtual Family Day on 22 May

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

NHS Secretariat	020 3758 2042 x 2
Norlan Dubissette	0207 794 0500 x 32909
Scleroderma Nurses Help-line	0207 830 2326
Clinical Trials	020 7317 7544
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



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Scleroderma Family Day – Saturday 22 May 2021

25th Anniversary Meeting

Zoom Virtual Meeting, Royal Free Hospital, Pond Street, London NW3 2QG

Chair: Professor Chris Denton

Please check the Royal Free website nearer the time for the Zoom login and final programme

<https://www.royalfree.nhs.uk/services/services-a-z/scleroderma/scleroderma-family-day/>

PROVISIONAL PROGRAMME

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 Rory Maclean
11:25-11:50	Pulmonary hypertension and the heart	Dr Gerry Coghlan
12:00-13:15	Lunch break	
13:15: 13:45	Scleroderma cohort studies - “Learning from our patients”	Dr Francesco del Galdo
13:45-14:15	25 years of progress - from “black box” to “positive trials”	Prof Chris Denton
14:15-14:45	International Speaker – Scleroderma Management in Netherlands	Dr Julia Spierings
14:45	Raffle	

