

Post-fellowship report SCTC

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Summary of activities

The SCTC visiting fellowship was invaluable for me in developing and maintaining research collaborations with the centre at the Royal Free Hospital. Although we had established some collaborative work having a visit supported by SCTC really helped to progress this and the work now has additional funding and momentum. Many of these activities are highly relevant to clinical research in scleroderma and SCTC support is very much appreciated and will be acknowledged in any future related abstracts and publications.

During my visit at the Royal Free Hospital-University College London (RFH-UCL) in 2021 I participated in patient care at the Scleroderma Unit (outpatient clinic and inpatients) and I worked on two research projects.

The first research project focused on long-term outcomes of patients with rapid progressive disease. In the large longitudinal cohort of the RFH, I studied patients meeting the inclusion criteria of autologous stem cell transplantation trials, but who were treated with conventional immunosuppressive therapy. My analyses showed that progression free survival in these patients was similar on the short-term when compared to transplant patients. However, outcomes at 10 and 15 years were better in the transplanted patients.

The second project was set up in response to the COVID-19 pandemic. As many patients were not able to visit the hospital for their routine visits, consequently monitoring of disease activity was limited. Therefore, we developed a simplified instrument for patients to self-assess their skin (the PASTUL questionnaire). The first validation study was performed at the RFH and had promising results; skin scores done by patients using the PASTUL questionnaire correlated well with the modified Rodnan Skin Score done by a rheumatologist.

Ongoing collaboration between RFH and UMCU

My SCTC fellowship was especially used to take the abovementioned projects and the collaboration between our centres further.

Firstly, in order to gain more insight in the effect of different treatments in patients with progressive diffuse cutaneous systemic sclerosis, we are now analysing inflammatory and fibrogenesis markers from patients treated with autologous stem cell transplantation or conventional immunosuppressive therapies, by using samples from the ASTIS trial and the RFH cohort.

Secondly, the PASTUL project is currently validated in other centres in the UK and longitudinally at the RFH. This project is supported by a grant from SRUK (Scleroderma and Raynaud's United Kingdom). Also, are validating the PASTUL questionnaire in the Netherlands.

Thirdly, this year we will start a new collaborative project on hand function impairment in systemic sclerosis.

Publications

This visiting fellowship at the RFH resulted in the following publications;

1. Spierings J, Ong VH, Nihtyanova S, van Laar JM, Denton CP. Outcomes linked to stem cell transplantation trial eligibility in diffuse cutaneous systemic sclerosis. *2022 May 5;61(5):1948-1956.*
2. Spierings J, Ong VH, Denton CP. PASTUL questionnaire: a tool for self-assessment of scleroderma skin during the COVID-19 pandemic. *Ann Rheum Dis 2021 Jun;80(6):819-820.*
3. Denton CP, Spierings J. Combining datasets as well as therapies shows improved outcome in connective tissue disease associated pulmonary hypertension. *Arthritis Rheumatol. 2021 May;73(5):725-727*
4. Spierings J, Denton CP. Chapter. Systemic sclerosis. In: *Oxford Textbook of Rheumatology 5th Edition (2021)*
5. Spierings J, Ong VH, Denton CP. Three cases of systemic sclerosis with different antibodies and clinical features within one family. *J Rheumatol 2022 May;49(5):544-546.*

The results have been presented at several scientific conferences as poster or oral presentations at the BSR annual conference, EULAR conference, ACR annual conference and the annual conference of the Dutch Rheumatology Society.