



Report of the short-term visit ERN Exchange Programme 2021-2022 ERN ReCONNET

Name of the participant	Vera Bernardino
Healthcare provider where the participant is employed	Centro Hospitalar Universitário Lisboa Central, Lisbon, Portugal
Name of the Healthcare provider and Head of the Unit hosting the exchange visit: Madelon Vonk	Radboud University Medical Center Geert Grooteplein Zuid 10, 6525 GA Nijmegen, Netherlands
Start date of the exchange visit	22.01.2023
End date of the exchange visit	29.01.2023

1. Please introduce your position/employment (MD, HAP, patient, other) and years of practice of your profession:

I'm a medical doctor for 14 years now. I am an internal medicine and autoimmune disease specialist.

2. The objectives of the exchange visit were:

- Sharing of clinical and organisational knowledge on rare connective tissue diseases (rCTDs) aimed at improving care.
- Education and training of healthcare professionals on rCTDs.
- Sharing good practices on rCTDs.
- Support of patient empowerment and education on rCTDs.

3. Please describe the activities performed during your exchange visit:

During my exchange visit, I had the opportunity to join the different activities of the rheumatology department:

- **Rheumatology and Skin Outpatient Clinic** – patients were observed by Rheumatology (Dr Rogier M Thurlings) and Dermatology (Dr EMGJ de Jong) together, at the same time. Each case was discussed separately and diagnostic and treatment approaches were decided and explained to the patients. Most patients had eosinophilic fasciitis, imposing an important differential diagnosis with morphea - a localized form of scleroderma.

- **Rheumatology Outpatient Clinic** – with Prof. Madelon Vonk, Dr Iris van Ingen, Dr Sander van Leuven. The Radboud UMC Rheumatology Department is a national reference center for systemic sclerosis, so there were patients from all over the Netherlands. Therefore, most of the patients observed



had systemic sclerosis, with different degrees of severity and organ involvement. I also had the opportunity to observe patients with other rare autoimmune diseases of the connective tissue, such as Sjögren's Syndrome and Systemic Lupus Erythematosus.

- **Pulmonary Hypertensive Disease Outpatient Clinic** – with Dr Hanneke Knaapen-Hans. Patients with systemic sclerosis and pulmonary arterial hypertension are observed in the hospital, in sequential consultations of Rheumatology and Cardiology. They are also accompanied by nurses specialized in this type of complications, who adjust the medication, the diet and prescribe any necessary nutritional supplements.

- **New Patients Immunology Clinic** – with Dr Chantal Bouman, a Rheumatologist in training, who would further discuss the patients with an attending. We observed new patients with systemic sclerosis and one patient for study (sicca syndrome associated with tubulointerstitial nephritis).

- **Clinical Meeting and Staff Discussion** – Every morning there is a medical staff meeting to discuss hospitalized patients and review the daily tasks assigned to each element. Once a week, there is a clinical meeting in which complex patients are extensively discussed, with the participation of all service elements, medical assistants and nurses.

- **Nailfold Capillaroscopy Clinic**, with a physician-assistant in training.

- **Inpatient medical visit** - During my stay at the service, patients were hospitalized for systemic sclerosis (recently submitted to stem cell transplantation), systemic lupus erythematosus (cutaneous involvement and constitutional condition), ANCA vasculitis (therapeutic induction with rituximab), rheumatoid arthritis (restaging and optimization of therapy), sarcoidosis of the central nervous system (hospitalization for brain biopsy) and gouty polyarthritis (therapeutic guidance).

- **Day Hospital** – for patients admitted during the day for administration of intravenous therapy. The advisory team was called in to treat adverse reaction to infliximab.

- **Journal Club**, presented by one of the Rheumatology doctors in training, “Anti-CD19 CAR T cells for refractory SLE” (Mackensen A, et al. Nat Med. 2022 Oct;28(10):2124-2132. doi: 10.1038/s41591-022-02017-5. Epub 2022 Sep 15)

4. Please describe below what you have learned and which new information/novelties you got during the exchange visit:

During this incredible learning experience, I had close contact with a multidisciplinary referral team for patients with systemic sclerosis. Thus, I was able to observe many patients with this disease, with different types of organ-involvement and serious complications, and understand what kind of approach each professional can provide to these patients. Also from a learning perspective, as the medical team has an extensive experience in immunosuppressive drugs and stem cell transplantation, the discussion of therapeutic options in each patient was very important to me.

In addition to the other more frequent rCTDs observed, which I have the opportunity to follow up at my centre, the experience of observing so many patients with eosinophilic fasciitis has awakened the importance of the differential diagnosis with localized scleroderma (morphoea), that should always be performed through a multidisciplinary and specialized approach.



The in-hospital articulation is essential for the timely management of complications, so coordination with dermatology, cardiology and other specialties is very important. On the other hand, it was important to realize that, with a good support network in primary health care, it is possible to delegate to family doctors the management of other types of common illnesses (diabetes, arterial hypertension, dyslipidaemia, etc.), the follow-up vaccination plan, referral to rehabilitation centres (for physiotherapy), psychological support, etc. The articulation with the family doctor is essential, especially in terms of communication and information sharing: it is essential that he is aware of the patient's diagnosis, the therapeutic plan outlined, treatment' possible complications and the possibility of managing minor damage in an outpatient setting.

Lastly, being these doctors so experienced in research, their curious, challenging and systematic attitude with which they approached patients and diseases, stimulated the need to expand our own research projects even further.

5. Please describe below how you plan to implement what you have learned in your Healthcare provider/clinic/practice:

Our centre is made up of a young and dynamic team, willing to learn and expand their knowledge. Therefore, I will propose to my team the creation of specialized consultations in some more complex diseases, such as systemic sclerosis or systemic lupus erythematosus, in order to speed up the multidisciplinary articulation and facilitate the referral of these patients. We will encourage the training of our nursing team and get them used to managing some aspects of therapy and patient follow-up.

On the other hand, we are going to optimize the communication channels with the family doctors and prepare documentation to make them aware of particular issues in autoimmune diseases - such as the control of cardiovascular risk factors and family planning.

As for the patients, we will also develop new communication strategies, together with patient organizations, in order to keep the updated and empower them on how to manage their own illness.

As for research, we want to optimize strategies to allow our doctors (including fellows, trainees and interns) to be able to develop more projects, participate in more clinical trials and carry out ongoing PhD programmes.

6. Would you visit in the future the same center or another ERN centre for update/new topics?

This visit represented a great learning opportunity for me. Undoubtedly, I would like to do a short fellowship again at the Radboud UMC hospital, or even at other centres of the ERN RECONNET.

7. Would you recommend the Exchange Programme to your colleagues? If yes, why?

Yes, I would totally recommend it. This programme represents a great opportunity to learn with other colleagues, experts in rCTDs, in order to improve our own practice, as physicians, but also as researchers.

This experience allowed me to grow as a doctor, gathering me additional skills, capabilities, know-how and knowledge to better treat our patients, share knowledge with our younger interns and medical students and teach other healthcare providers, as nurses, empowering them.

By learning from the best, we are able to import the best clinical practice into our own center. In this way, this will help us to ameliorate and reshape the medical care to autoimmune patients in Portugal.