

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

Name of the participant	Daniela Carabott Pawley
Healthcare provider where the participant is employed	Mater Dei Hospital, Malta
Name of the Healthcare provider and Head of the Unit hosting the exchange visit Address Name of the Head of the Unit	AOU Meyer Florence Head of the Unit Prof. Gabriele Simonini
Start date of the exchange visit	16-01-2023
End date of the exchange visit	27-01-2023

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

I am an Allied Health Professional – Physiotherapist, specialising in paediatrics care. I have been employed within the public services since 2013, and working in paediatrics acute care and rehabilitation since 2018.

2. The objectives of the exchange visit were:

- Familiarise myself with the presentation of some rare connective tissue and musculoskeletal conditions.
- Develop my knowledge on the management of rare diseases and conditions.
- Possibly help in further development of our paediatric physiotherapy services locally.
- Facilitate networking with professionals already working in the area

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

I have spent 2 weeks within the Rheumatology out patients department. I attended the joint clinics held between the rheumatology and the physiotherapy teams. I also had the opportunity to spend some time with the physiotherapy team at the rehabilitation centre.

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

During this visit I had the opportunity to witness the whole process of diagnosis, management and also discharge stages of different inflammatory conditions from the medical point of view, together with the parallel physiotherapeutic management. The conditions seen at this centre cover a wide range of



muskuloskeletal and connective tissue disorders, including some which I was familiar with, some which I knew about only from textbooks and some which I was completely new to. Some conditions which I have encountered during this visit were, Idiopathic Juvenile arthritis, Systemic Lupus Erythematosus, Kawasaki disease, Uveitis, Hypermobility spectrum disorders and CACP. One very important learning aspect during this visit was the familiarisation with the common diagnostic tests, clinical presentations and yellow/red flags which present in these conditions.

Spending time at the rehabilitation centre, offered me the opportunity to analyse the current local management of these conditions in comparison to that offered at this centre. This helped in identifying weaknesses and strengths in our current management and also further plan progress.

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

This visit helped me to understand the importance of building a network within the MDT when managing rare diseases. Being rare in nature, implies that as clinicians we might not be so familiar with the presentation of these conditions, therefore frequent, close communication within the team will ensure that nothing is missed and that the patient and their families are offered the best form of care available within our system.

The use of some objective measures and assessment strategies adopted within this centre can also help improve the service provided within our locally service.

The contacts created during this visit can also serve as a source of assistance and possible reassurance, whenever a new rare condition presents at our department.

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

I would definitely like to visit this centre again, as two weeks are a very limited period of time. This centre has a lot more to offer to clinicians such as myself, not simply from the rheumatology department but also within other sections. I would also like to visit other ERN centres, to further my knowledge and help develop the service we provide locally, whilst enhancing my professional network.

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

Yes. Working in a small island with one general hospital often means that we are faced with a large number of rare conditions, which on an individual basis are rare but collectively add up to a substantial number. Formal education is very essential but also limited when dealing with rare diseases. On the other hand, experience may be difficult to develop in such small countries, therefore visiting other larger centers will help us attain the experience and expertise necessary to help provide good quality care to these individuals living with rare conditions and their families.

These visits also offer the opportunity to build strong networks between different centers and clinicians, ensuring that patients all across the EU can receive good quality care, irrespective of the size of their countries of residence.