

Report of the short-term visit

ERN Exchange Programme 2021-2022

ERN ReCONNET

Name of the participant	Charissa Frank
Healthcare provider where the participant is employed	International Scientific Symposium on EDS
Healthcare provider hosting the exchange visit	
Start date of the exchange visit	13-09-2022
End date of the exchange visit	18-09-2022

1. The objectives of the exchange visit were:

1. Attending the International Scientific Symposium and participating in sessions and workshops,
2. Networking with the international experts taking part in this event, both speakers and attendants.
3. Meeting and networking with other Patient Organizations, especially those from ReCONNET. Exchanging best practices and challenges.
4. Meeting Disease Coordinators and other participants in the EDS group from and being able to discuss relevant issues related to the work in the ERN face-to-face and strengthen our team.

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

I attended all the main sessions on the program where the newest information, research or insights were presented and discussed all types of EDS. During breaks, I took the opportunity to network with other clinicians and patient advocates to further expand the EDS network and to identify and prioritize the needs/red flags etc. for the EDS WG. Some members of the EDS WG met to discuss possible red flags to start the discussion for the EDS WG meetings. Eva and I also took the opportunity to meet face to face and start planning for the upcoming WG meetings with the only disease coordinator present.

3. Please describe below what you have learned during the exchange visit:

The conference was very educational as well as an excellent opportunity to network with others in the EDS field clinicians and patient advocates. It allowed me to learn the latest news, development of the different types as well as hearing what is happening in the different countries around Europe. A few minutes face to face can be more enriching than a survey or an email.



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

I intend to apply the newly gained knowledge to help steer and represent the patient community in the EDS and other workgroups. It will further help me to engage the EDS community and represent them even better as a whole.

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

I recommend all ePAG advocates and clinicians to partake in the Exchange Programme because it will help the ERN become a success story. The Exchange Programme, through education, will help cross-border care and the different disease communities going forward.