**ERN-RND Network Annual Meeting 2024**

On 10 and 11 of October the Annual Meeting of the ERN-RND network took place in Ljubljana in Slovenia.

About 60 experts from all over Europe travelled to take part while 30 participants and some of the speakers joined via Zoom.

Local organiser Dr. Ales Maver and ERN-RND project leader Prof Holm Graessner from Tübingen, Germany welcomed the participants.

Prof Graessner gave a report on the activities of the past year. There are now 68 expert centres including 4 supporting centres, in 24 EU countries taking part serving all together over 44 000 patients.

The core activities of the network are:

• Cross border healthcare/CPMS

• Training and education of healthcare professionals

• ERN-RND Registry

• Guidelines and Clinical Decision Support Tools/care standards

• Patient journeys

• Dissemination

The ePAGs (patient representatives) of the network: Astri Arnesen, John Gerbild and Monika Benson then gave a presentation on ‘How to make the patient journey better?’

A powerful video from the WHO about people-centred care was shown. If you are interested you can watch it here: <https://www.youtube.com/watch?v=pj-AvTOdk2Q>

John Gerbild from Denmark gave a moving testimony of an ataxia patient he met some time ago and this man mostly misses being able to cook delicious meals.

Monika showed the Dystonia Physio Hub and how this can be one of the tools/steps to a multidisciplinary care for cervical dystonia patients.

After lunch we attended the scientific symposium with various expert presentations on EU initiatives on rare diseases and research opportunities, training programs, drug development.

The second day there were meetings for the different working groups. One of them focused on Dystonia, NBIA (Neurodegeneration with Brain Iron Accumulation)and Paroxysmal Disorders. Here is the opportunity for the specialists to share updates on various activities and projects as well as discussing new ideas.

For more information on the ERN-RND visit: <https://www.ern-rnd.eu>