



European
Reference
Network

Connective Tissue and Musculoskeletal
Diseases (ERN ReCONNET)

4th ERNs conference *“ERNs in action”* report

21st – 22nd November 2018 | Brussels



4th ERNs conference “*ERNs in action*”,

21-22 November 2018, Brussels

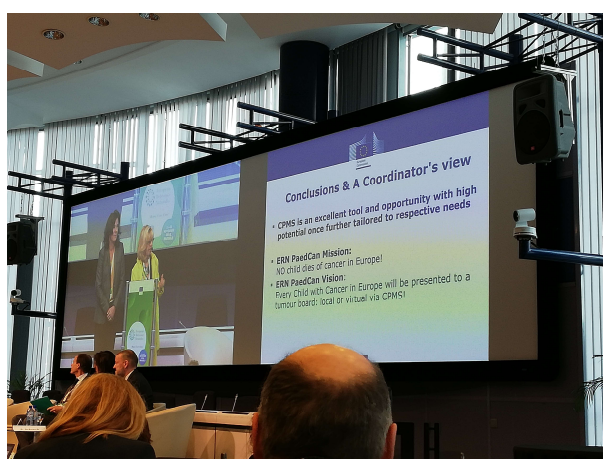
The 4th ERNs conference took place in Brussels on 21st and 22nd November 2018. More than 400 attendees from the ERNs community gathered in the two-day event, including ERNs coordinators, patients representatives, hospital managers, policy makers, delegates of the European Commission and representatives of Healthcare Providers from the different ERNs.

After the ERNs kick-off in Vilnius in 2017, the 24 ERNs are now fully operative across Europe. The objective of this conference was to discuss and explore the achievements obtained during this period and identify challenges and potential improvements for the future of the Networks.



Different transversal topics were discussed during the plenary and parallel sessions, such as the integration of the ERNs in the national health system, the development and implementation of Clinical Practice Guidelines, the partnership between Patients and Healthcare Professionals in the ERNs, the importance of the Clinical Patients Management System and the central role that the ERNs can play in rare diseases research and cross border healthcare.

The main priorities for 2019 will be the improvement of the geographic coverage of the Networks, (which will be addressed in the next call that will be launched by the European Commission) and the integration of the ERNs into national Health Systems, a topic that was highly considered also by the Representatives of the Board of Members States and the Hospital Managers that attended the conference.



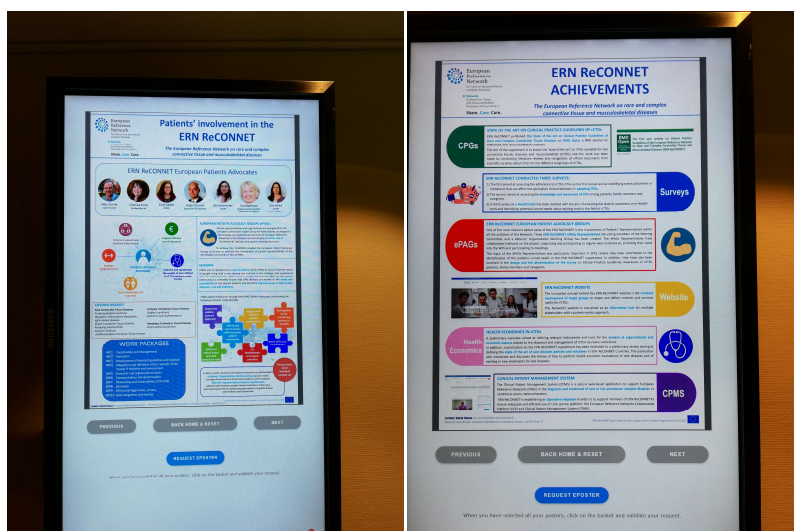
The ERN ReCONNET was represented during the conference by:

- Marta Mosca, ERN ReCONNET Coordinator
- Maurizio Cutolo, Deputy
- Sara Cannizzo, Project Manager
- Joao Cabral de Fonseca, Member of the Steering Committee
- Charissa Frank, Member of the Steering Committee, ePAG Advocate
- Ilaria Galetti, Member of the Steering Committee, ePAG Advocate
- Eric Hachulla, Member of the Steering Committee
- Diana Marinello, Project Manager
- Carlo Milli, Hospital Manager of the Azienda Ospedaliero Universitaria Pisana
- Matthias Schneider, Member of the Steering Committee
- Vanessa Smith, Member of the Steering Committee
- Ana Vieira, Member of the Steering Committee, ePAG Advocate



The ERN ReCONNET delegates at the 4th ERNs conference

The ERN ReCONNET Coordinator, Marta Mosca, presented during the parallel session 1 “ERNs showcases” and 2 ERN ReCONNET posters have been displayed during the conference.



The ERNs commitment for the improvement of the care provided to rare diseases patients across Europe was reflected in the updates provided on the numerous activities that are ongoing in the different ERNs on mapping and creating Clinical Practice Guidelines and on the high value of the Clinical Patient Management System. The Commission has provided support to the ERNs on both topics, launching a tender for the development of Clinical Practice Guidelines and providing funds for the management and the implementation of the Clinical Patient Management System.



The challenges identified included the long-term sustainability of the ERNs, especially on the provision of funding, on the need to raise awareness in the rare diseases community and the heavy burden on ERN experts due to the limited human resources available and the limited pool of experts existing. These challenges highlighted the importance of providing a sustainable framework for the continuation of the ERN infrastructure, as stated by the Commissioner for Health and Food Safety, Vytenis Andriukaitis *“Expertise is being shared, developed, and expanded across Europe – increasing the capacity of specialists and health care and cure systems. We have to believe in our success and continue to work in our cooperative spirit.”*

The video recording of the conference and a summary report are available on the European Commission’s website: https://ec.europa.eu/health/ern/events/ev_20181121_en. A more detailed report and the pdfs of the presentations will also be available at the same link.