



Dr. Enrique Terol
Policy Officer
SANCO – D2 Healthcare Systems
European Commission

Re.: Collaboration between the Multidisciplinary Joint Committee of Rare and Undiagnosed Diseases (MJC-RUD) of UEMS and the European Reference Networks Coordinators Group (ERN CG)

Dear Dr. Terol, dear Enrique,

As you know, the European Union of Medical Specialists (UEMS) aims to improve standards for high quality healthcare practice in order to support the Authorities and Institutions of the EU as well as the National Medical Associations. Within the UEMS, Multidisciplinary Joint Committees (MJC) address areas which are of a professional multidisciplinary nature. The MJC for Rare and Undiagnosed Diseases, the MJC-RUD, was established in 2016 to bridge the gap between medical specialist societies and to facilitate high quality multidisciplinary diagnosis and care for people with rare or undiagnosed conditions.

European Reference Networks (ERNs) are expected to improve the care for patients with rare diseases. Therefore, the MJC-RUD welcomes the 24 newly established European Reference Networks. The ERNs are established in frame of the directive cross border health care, Directive 2011/24/EU. The directive defines a health professional as a doctor of medicine, a nurse responsible for general care, a dental practitioner, a midwife or a pharmacist within the meaning of Directive 2005/36/EC. With the experience that exists within UEMS with regard to setting training standards, developing syllabi, developing teaching materials and setting criteria for assessment by the different medical societies, we propose to build a structural collaboration between the MJC-RUD and the ERN's.

Specifically, there are two important issues where we could work together with the 24 European Reference Networks:

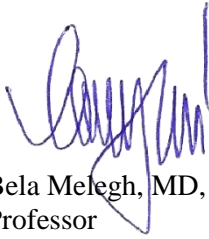
- provide of a common core training principles of rare diseases for MJC RUD participating medical specialties with the help of the ERN CG, and ultimately with the individual education working groups later;
- collaborate in EACCME CME accredited training programs both on site like courses and conferences and by e-learning, as the EACCME of the UEMS is the main EU scientific event accreditation body.

As a first step, we would contact the leaders of the ERN CG asking their willingness about partnering in specialist training within the ERN CG framework issues "Knowledge generation: Training, education, capacity building; guidelines development" task package. Later, when this partnership already established, we would more specify the necessary further steps.

Currently, several medical disciplines within the UEMS already offer specialist training in rare diseases. Therefore, we are also interested to learn how the leaders of the 24 ERNs envisage to contribute to these existing training programs. Specifically, as rare diseases disproportionately affect children, we are looking forward to your thoughts about how we can ensure that their specific needs are also addressed in future training programs.

We hope you find our offer useful and look forward for a possible collaboration to improve health care for European citizens with rare disorders, and will support our initiative.

With best personal regards,



Bela Melegh, MD, PhD

Professor

Chair UEMS Section for Clinical Genetics

Chair UEMS MJD for Rare and Undiagnosed Diseases