



# UNION EUROPÉENNE DES MÉDECINS SPÉCIALISTES EUROPEAN UNION OF MEDICAL SPECIALISTS

*Association internationale sans but lucratif*

*International non-profit organisation*

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## UEMS MJC RARE AND UNDIAGNOSED DISEASES

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### Minutes of the Kick-off Meeting of the MJC Rare and Undiagnosed Diseases (MJC-RUD)

20th October 2016, Brussels, Belgium

***Motto: "Communication – Quality – Clinics"***

Present:

Alexandre Bisdorff, Luxemburg

Nursel Calik Basaran, Turkey

Nada Cikes, Croatia

Rijk Gans, Netherlands

Marc Hermans, Belgium, UEMS

Daniela Karall, Austria

Ulf Kristoffersson, Sweden

Norbert Lukan,

Patrick Magennis, UK

Jaime Medrano, Spain

Bela Melegh, Hungary, President

Udo Rolle, Germany

Liesbeth Siderius, Netherlands

Grazyna Slaveta, Poland

Enrique Terol, Spain

Aivars Vetra, Latvia

Lotte Welinder, Denmark

Kristiina Aittomäki, Finland, Secretary

At the beginning of the meeting Prof. Melegh gave a short presentation on UEMS and its important role in educational harmonization in Europe. He also informed the participants that Prof. Papalois was unable to attend.

1. The meeting was officially opened by Prof. Marc Hermans, who attended the meeting as the representative of UEMS. The delegates introduced themselves.

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2. The agenda that had been circulated to the registered participant was approved.
3. Professor Hermans introduced the UEMS Rules of Procedures (ROP) on multidisciplinary joint committees. The purpose of the bureau of MJC is to coordinate actions, circulate information, and prepare documents for the MJC. More information can be found on the UEMS website under Explanatory notes.
4. Election of the Bureau for the Multiple Joint Committee. Every MJC needs to have a bureau of at least two officials, President and Secretary. There was one candidate for both positions from the Section of Clinical Genetics, the President Professor Bela Melegh from Hungary and the Secretary Professor Kristiina Aittomaki.

Professor Melegh was elected as the President and Professor Aittomaki as the Secretary to the MJC-RUD.

5. Future activities of the Section, possible goals of MJC RUD

Prof. Melegh gave an introduction to the discussion. He noted that many European projects include educational packages, but at the end of these projects often very little has been done to actually enhance professional education. Furthermore, professional training on rare and undiagnosed diseases is presently weak. As high-quality education is one of the aims for the UEMS, the MJC-RUD could aim at enhancing training on rare and undiagnosed diseases. The strength of the MJC-RUD is that it includes many specialities and can reinforce any produced documents on the European level through UEMS Council meetings. He also encouraged all delegates to participate in the discussion on the aims of MJC-RUD.

There was a lively discussion on the problems on how to deal with the multitude of rare diseases. It was noted that future doctors need expert skills in IT. Although much information is available also for the patients in the internet, we need capable specialists between the patient and Doctor Google and European harmonization to improve patient care. It was also noted that within the MJC-RUD it is possible to discuss and share both problems and experiences and that would benefit educational development.

Professor Hermans pointed out that there are three central items to consider (in bold): You need **communication** to improve the **quality** of care in the **clinic**.

One of the important goals for the MJC-RUD is to create awareness of the ERNs, when they are working, and to give advice to patients and doctors how to contact them.

6. Introduction to the present state of European Reference Networks by Dr. Enrique Terol, Policy Officer of European Commission

Copies of Dr Terol's presentation will be circulated.

Short notes from the meeting:

ERNs have a legal base in European Union legal structure. Presently there are 24 applications for ERNs including 18-77 centres. Almost all countries have recognised the ERNs. The idea is not to establish networks for individual diseases, as hundreds of ERNs cannot be created, but broader thematic networks.

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ERNS are a new environment of health care as they deal with patients that cannot be dealt with in their national health care and therefore need international healthcare. The idea, however, is that patients do not travel, knowledge travels. This arises questions such as “how do we incorporate this within national healthcare systems” and “how to organize nationally the flow of patients”. The treatment of patients should preferentially be organized on national level. While the ERNs can give advice on how and where the patients should be treated, the member states can approve or deny their suggestions.

Questions to Dr Terol:

As the patients have overlapping symptoms, do the ERNs work together?  
Meetings of the coordinators of the ERNs are organized and they are discussing on how they can work together on complex clinical situations. E-health platform is a possibility for interactions.

Do the ERNs treat the patient?

Basically the ERNs offer virtual health care, but they are included within the cross-border healthcare directive.

How can the MJC-RUD work with the ERNs?

MJC-RUD could have a very important role as an advisory body, introduce tools for any approach for patients or diseases, work on other areas such as training.

ERNs could ask us to help them rather than us intruding within their area.

We could perhaps participate in the meeting of coordinators to explain what the MJC-RUD is doing. Both parties should know what each does, goals and overlapping areas. In general, MJC-RUD should develop a document to explain what we are doing to other organizations working in the field of Rare and Undiagnosed Diseases.

7. Future meetings of the MJC-RUD will be organized in association with UEMS meetings. Between the meetings the participants will keep in touch via “group email”.
8. A group photo of delegates was taken and the meeting was closed at 11.25

Brussels October 21, 2016

Kristiina Aittomäki, Secretary