

MULTIDISCIPLINARY JOINT COMMITTEE ON RARE AND UNDIAGNOSED DISEASES

Annual Report of the President - 2017

MJC RUD meeting, 20 October, 2018

The calendar year of 2017 was the first full year in the history of the MJC RUD.

Membership

We had a total of 34 members from 11 Sections (OMF, IM, Ophthalmology, Paediatrics, Psychiatry, Rheumatology, Medical Genetics, Neurology, Paediatric Surgery, Pharmacology, and Rehabilitation. They represented 21 Countries, of them 3 were non EU Nations (Armenia, Georgia, Turkey).

The Bureau

The Bureau consisted of the President and an acting Secretary.

Meetings

According to the official policy of the UEMS, physical meetings of MJCs are scheduled in the spring series of the UEMS Council only in exceptionally burning cases. As we did not have such an issue, in Tel Aviv there was no MJC RUD meeting.

The Membership meeting was scheduled to the winter UEMS season; the Minutes are enclosed. The Presided excused as the meeting was interfered with other professional commitment of him. Ulf Christoffersson was the acting president, there were 5 attendees altogether (5/34, 20.8% of the membership; 5/11, 45.4% of sections). According the UEMS RoP, the meeting was void as a valid Membership meeting due to the low admittance rate.

There was an informal gathering in association with the Kickoff meeting of ERNs in Vilnius on 8th March of 2017 (participants: Ulf Kristoffersson, Bela Melegh, Alessandra Renieri, and Liesbeth Siderius from the UEMS). The participants agreed to contact Enrique Terol and initiate a partnership of the MJC RUD in the education development in the emerging ERNs. Later a letter of intent, approved by the MJC RUD membership, was submitted to Dr. Terol, who extended an invitation to the president to present a lecture (RD Action Workshop for ERN, 6-7 December, 2017; the presentations with summary could be found on the pages of the event (see # 18): https://drive.google.com/drive/folders/1yQNjcYiNWc3EBNCWtkUU1RxcrpXoEhL4

Main focus in 2017

Albeit we were not officially affiliated partners, a main focus was a voluntary participation in some part the Joint Action on Rare Cancers (JARC) WPs, especially in WP8 (Medical Education). This promised multilateral mutual advantages, and help the support of the UEMS Exec and other Sections were since the preparatory phase of it back to 2016.

Thus, we participated in the "Medical Education Survey", in which survey the officially UEMS recognized medical professions were included as subjects of analysis. Besides the MJC RUD members, all UEMS professionals could participate, as the UEMS Exec helped to circulate it alongside the professional communication channels, and due to this support 72/104 (69.2%) of the responders were from the UEMS. The evaluation of the survey already revealed quite remarkable points, the finalization is still on the way; as other MJC RUD WP activities are also on the way in years of 2018 and 2019.

The web

The web of the MJC RUD was running under the hardware background of the Section of Medical Genetics. Meanwhile, this was just a technical help, our web management was independent.

Finances

During the year 2016 there was no budget or income of the MJC RUD. However, the president evaluated 4 life events for the CESMA.

Participation in other activities

Ulf Kristoffersson had a physical meeting with Enrique Terol in Brussels in October. The president participated in the work of the EACCME "Training the reviewers" working group.

On behalf of the Multidisciplinary Joint Committee of Rare and Undiagnosed Diseases:

Béla Melegh President