



Annual Report of the President – 2020

10 October, 2021

The calendar year of 2020 was the 4th full year in the history of the MJC RUD. Unfortunately, the Covid 19 pandemic strongly influenced our activity, however, we closed a quite productive year.

Membership

According to the last control, we recorded a total of 47 members from 27 Sections (OMF, IM, Ophthalmology, Paediatrics, Psychiatry, Rheumatology, Medical Genetics, Neurology, Paediatric Surgery, Pharmacology, and Rehabilitation). They represented 21 Countries, and of them 3 were non EU Nations (Armenia, Georgia, Turkey). This is an increase. The following NMAs have delegates: Austria, Georgia, Greece, Spain, The Netherlands, Turkey. However, some members indicated their resignation, indirect evidence suggest that some of the members on the list are not active. Therefore, a “housekeeping” is on the way with the assistance of Marine Boulard at the Coordination.

The Bureau

There was an electronic vote organized by the Coordination; Dr. Domenica Taruscio was elected as vice-president, and Dr. Artur Beke was elected as treasurer, the president was re-elected, all for terms started 2021 January. The Bureau consists of the president, secretary, treasurer, and 2 vice presidents.

MJC RUD Meetings

There was no official membership meeting during the year. All of our activity was conducted via emails.

Main focus in 2020 and after

Council approved the ETR of Rare and Undiagnosed Diseases (79.95 % support), Rare Adult Solid Cancer (68.42% support), and the ENETS ETR (88.89% support):

1. The ETR for "Rare and Undiagnosed Diseases", which consist of the next files:
 - Training Requirements for the Specialty of Rare and Undiagnosed Diseases (15 pages, number: UEMS 2020/12)
 - Description of “Rare and Undiagnosed Diseases” as a Medical Competency in EU: Aims and objectives for competency training (6 pages, number : UEMS 2020/12)
 - Syllabus for residents and trainees in Rare and Undiagnosed Diseases (13 pages, number: UEMS 2020/12)

2. The European training requirements for the specialty of "Rare Adult Solid Cancers", which consist of the next files:

- Training Requirements for the Specialty of Rare Adult Solid Cancers (17 pages, number: UEMS 2020/11)
- Description of "Rare adult solid cancers" as a Medical Competency in EU: Aims and objectives for competency training (10 pages, number: UEMS 2020/11)
- Syllabus for residents and trainees in Rare Adult Solid Cancers 513 pages, number: UEMS 2020/11)

3. European training requirement for "Neuroendocrine Neoplasia Medicine", which is a collaborative effort of the MJC RUD and the European Neuroendocrine Tumor Society (ENETS). (18 pages, number: UEMS 2020/09).

The next priority is the organization of the European Board of Rare and Undiagnosed Diseases, and then the European Exam.

Home page

As the web was associated to the Section of Medical Genetics (SMG) as a courtesy of the provider to Dr Melegh, SMG president, this was not available after 2021 January, as the term of Dr Melegh expired.

Finances

At the moment 889.1 Euros budget of the MJC RUD is available, we already paid 300 Euros CESMA membership contribution for 2021. The president evaluated 6 life events for the CESMA. The president requested support from the UEMS Exec, unfortunately the request was rejected 3 times.

Participation in other activities

A Memorandum of Understanding (MoU) was signed with the Undiagnosed Network International (UDNI). This MoU could be a base of further strong collaboration in education fields primarily. The president participated in the work of the CESMA, and continued with the EACCME "Training the reviewers" working group.



Béla Melegh
MJC RUD President