

# **MULTIDISCIPLINARY JOINT COMMITTEE ON RARE AND UNDIAGNOSED DISEASES**

# Annual Report of the President – 2019

10 February, 2020

The calendar year of 2019 was the third full year in the history of the MJC RUD.

### Membership

We had a total of 39 members from 11 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). The following NMAs have delegates: Austria, Georgia, Greece, Spain, The Netherlands, Turkey.

### The Bureau

There was an electronic vote organized by the Coordination; Pr. Alessandra Renieri was elected as Secretary, and Serdar Ceylander as vice President. The Bureau consisted of the President, Secretary, and a vice President.

#### Meetings

There was no official membership meeting during the year. However, both the President and the Secretary participated at the London UEMS Council Meeting, and there was a non-official gathering of the participating MJC RUD members.

#### Main focus in 2019 and after

Construction of ETR of Rare and Undiagnosed Diseases, Rare Adult Solid Cancer, and the ENETS ETR.

#### Finances

During the year of 2019 there was still no independent budget of the MJC RUD. However, the president evaluated 5 life events for the CESMA.

## Participation in other activities

The president participated in the work of the CESMA (talk at the Barcelona meeting), and continued with the EACCME "Training the reviewers" working group. There was a meeting with the ENETS representatives.

Béla Melegh President