

UEMS Multidisciplinary Joint Committee (MJC RUD)

UEMS European Board of Rare and Undiagnosed Diseases (EBRUD)

TERMS OF REFERENCE

June 2024

1. CONSTITUTION

- The MJC RUD was formed by the UEMS Council in 2015 at the request of the UEMS Section of Medical Genetics and is one of the MJC's in the UEMS. The EBRUD was formed by the UEMS Council in 2021 at the request of the MJC RUD.
- Both the MJC RUD and EBRUD conduct their activities according to the regulations of the UEMS RoP and Statues.

2. MEMBERSHIP AND GOVERNANCE

The members of MJC RUD and EBRUD Bureau and membership are from Sections or from NMA's. The MJC RUD can also delegate to EBRUD, European scientific societies can also send delegates to EBRUD in the optimum of 50-50% participation ratio.

The membership of MJC RUD and EBRUD will consist of (Bureau and Members):

- President: elected by membership vote. Role: coordination of activities of the committee according to the UEMS RoP paragraph for the UEMS Exec members.
- Secretary: elected by membership vote. Role: organize meetings, generate minutes of the meetings and support the President in coordinating activities, according to the UEMS RoP paragraph for the UEMS Exec members.
- Treasurer: elected by membership vote. Role: management of monetary affairs, separately in the MJC RUD account and the EBRUD account, respectively.
- Vice-President: elected by membership vote. Role: support the activities of the president, replace president by presidential appointment.
- Liaison officer (optional): elected by membership vote. Role: coordinate the partnering, inside and outside of the UEMS according to the UEMS RoP paragraph for the UEMS Exec members.
- All members are volunteers.
- 'Observers': colleagues interested in any field related to issues on rare disease tasks, chores of People Living With Rare Diseases (PLWRD) and who are invited by MJC RUD and/or EBRUD Bureau. Observers might not be UEMS members, they could be invited to attend meetings and to contribute to specific tasks.
- 'Collaborators': leading experts who are willing to work on specific topics, who are identified and invited by MJC RUD and/or EBRUD Bureau. Collaborators might or might not be UEMS members

All members, observers and collaborators of the MJCRUD and EBRUD must declare any interest that may conflict with their duties.

At any time, members may depart from MJC RUD and EBRUD, both the MJC RUD and EBRUD welcome new delegates at any time.

Member candidates interested in becoming a MCJ RUD and/or EBRUD member/collaborator/observer are requested to send their CV, and a letter stating their expertise and motivation for joining MCJ RUD and/or EBRUD to the UEMS Coordination and Secretary of MCJ RUD and EBRUD.

For the composition of the groups, expertise in a range of subjects and professional backgrounds is considered; members should have experience with or proven interest in policy issues regarding PLWRD and be motivated to work on specific topics, most notably with training and exam experience.

3. GENERAL POLICY

MJC RUD and EBRUD operates within the financial parameters set by the UEMS RoP and Statutes.

They have separate bank accounts and management.

All activities undertaken under MJC RUD and EBRUD guidance are non-remunerated activities.

Documents pertinent to the activities of the MJC RUD and EBRUD are transparent and are stored on the MCJ RUD and EBRUD websites.

All documents are first discussed by MJC RUD and/or EBRUD Bureau, then by the membership, with involvement of the UEMS Coordination/Bureau if necessary, later all approved documents are uploaded to the website to ensure transparency.

4. MISSION, DUTIES AND STRUCTURE:

The MJC RUD and EBRUD are sister bodies of the UEMS with strong overlap in their activities, which require tight collaboration of the Bureaus and members. Meanwhile there are topics devoted primarily to the MJC RUD or EBRUD and these are subjects of the specific Bureau and/or membership meeting decisions. The Treasurer is preferably the same person for both, but this is not necessary.

It is the mission of MJC RUD and EBRUD to contribute to the responsible translation of advancements in rare disease care, and therefore their members aim to identify and discuss the medical, ethical, social and policy issues related to persons living with rare diseases and its application in research, clinical practice and laboratory genetic profiles.

MJC RUD:

- According to the MJC rules of the UEMS, this MJC RUD has a leading position in EACME event certifications, maintaining communication with the Sections and external MJC RUD partners.
- Although the EBRUD is considered a "Working Group" both the MJC RUD and EBRUD have the right to establish their own internal sub-working groups for drafting and isolated purposes. These types of sub-working groups are liberal but have to do their activity in association with UEMS principals and have to be transparent.

EBRUD:

- Based on the UEMS roles on European Boards the goal includes to build a structure to involve as many European scientific societies as it is possible paired with the relevant UEMS Sections, in a ratio of 50-50%.
- As the EBRUD is permanently open to new sections, it is open to endorse the appropriate scientific societies as well. This makes a significant difference compared to other European Boards, since in other Boards one or a few European scientific societies are included in the EBRUD we envision a complex system with numerous boards and numerous partner societies.
- As the European Boards are education pillars of the UEMS in general, the primary competence of the EBRUD includes the governance of the European Exams, with collaboration of the CESMA.

5. FREQUENCY OF MEETINGS

The MJC RUD and EBRUD meetings will take place at least once a year, preferably within the context of the UEMS Council Meeting. Meetings are in person, online, or hybrid.