



Minutes MJC RUD Meeting Brussels

Friday October 20th, 2017 10.00-12.00

Chair: Ulf Kristofferson (Clinical Genetics)

Present: Nursel Celik Basaran (Turkey), Annick Vogels (Psychiatry), Ulf Kristofferson (Clinical Genetics) Rijk Gans (Internal Medicine), Liesbeth Siderius (Pediatrics)

Apologies: Lotte Wellinder (Ophtalmology), Oleg Kvlividze (Georgia)

1. Opening (by Ulf Kristofferson)

Ulf is apologizing Bela Melegh who is attending at American Society of Human Genetics meeting in the U.S.

2. Setting the agenda of today's meeting

Decision: Accept as it is.

3. Election of new secretary

Kritiina Aittomaki has stepped down. Liesbeth Siderius has been acting secretary since. An election have to be presided by a nomination procedure which the present board has missed. Liebeth Siderius has volunteered to continue as acting secretary of MJC-RUD

All candidates should make their candidature at least two weeks before the MJC meeting. This procedure has not started in time for this meeting. Therefore it is proposed that all MJC members can nominate a candidate. The members present favour the candidature of Liesbeth Siderius. In case there are no other candidates the function of acting secretary can become to the MJC's secretary.

Decision according to discussion above.

4. The role and function of a MJC compared to a section.

The draft document: Multidisciplinary Joint Committee (MJC) Rare and Undiagnosed Diseases (RUD) was discussed (171016 LS/PT/UK)

Discussion:

At present most training and research is appointed at national governmental level. Medical sections develop their training program at a European level. From the European training perspective there is a need for harmonized (international) care- guidelines.

To collaborate at a European specialty level in a RUD core training program recognized multidisciplinary guidelines are needed.

Also criteria and exam special qualifications, RD training requirements, should be established. Experts participating in ERN are assigned by the member states.

UEMS can bring training at a European level.

The draft has to be revised at least some points on training should be addressed.

Action: input from all

Decision: All agreed on the outline of the document. Document should be finalised before next MJC- RUD meeting

5. Minutes MJC-RUD meeting October 2016 and informal meeting in Vilnius April 2017

Decision: Approval

Information on the informal meeting in Vilnius: The president, Bela Melegh, the acting secretary and Ulf Kristoffersson met informally in conjunction with the first meeting of the ERNs and discussed way for collaborations between MJC-RUD and the ERNs.

6. Budget

The section has no income and no costs. All work is done voluntarily or costs covered by UEMS Sections or NMAs.

UEMS does not provide economic support to a MJC.

When the MCJ gets involved in CME accreditation there will be income from EACCME and a treasurer needed.

With questions on the multidisciplinary CME accreditation it is recommended to ask Vassillios Papalois, the chair of EACCME.

Action: Ulf

Outcome added to the minutes

7. MJC-RUD goals

Discussed under 4.

8. Report of the contacts with Enrique Terol / ERN's

Dr Terol did not respond on the letter send by the MJC RUD on collaboration with the ERN's. Ulf has taken the chance to make an informal appointment with him Monday 23th October. Outcome added to the protocol

Rijk stated the following :

The first issue's that should be addressed in the relation between UEMS and ERN's :

- ERN's should explain what they are doing
- MJC-RUD will explains what UEMS does (is responsible for) Then we talk about what activities we can share.

9. JARC WP8 (Joint Action Rare Cancers Work Package 8) Medical Education – Collaboration with MJC-RUD - JARC on a survey about rare cancers.

Ulf explains the activities of the JARC. Bela Melegh is WP leader and has suggested this collaboration.

The group is interested to receive more information on the education part; what

are the expected outcomes of this WP, and to know what the MJC could add.

10. Update on EACCME accreditation of training programmes in rare diseases

Ulf explains how the clinical genetics section has an accredited program for qualified laboratory technicians and laboratory geneticist and how they collaborate in a joint European board on harmonisation of training and education and for a European diploma for the non MD members.

In general there should be worked towards CME harmonization within network of different medical societies, and the UEMS has taken an initiative.

11. Logo of the section (Ulf Kristoffersen)

Two alternatives was presented.

Decision: The light blue logo selected (see head of document)

12. Web of the MJC RUD

Host the website within the UEMS is expensive, and Bela Melegh has offered to host the website for free under the umbrella of his university (Pecs, Hungary) similar to what he has done to the UEMS Section for Clinical Genetics.

A MJC RUD Website is under development

This website will be linked to UEMS, www.UEMS.eu.

Governance of the website: The person who can edit the website has to be connected to the University of Pecs, and thus through Bela Melegh.

Decision: Any item put on the website should be decided by the bureau of the MJC, with the secretary acting as the hub for collecting and editing the material.

13. Next meeting(s)

One meeting a year is not considered enough to generate sufficient activities. Proposed next MJC RUD meetings:

Spring UEMS meeting in Maroc (Marrakesh the last weekend in April)

ERN meeting in Barcelona

Decisions to be made by the bureau

14. Any other business

Nursel (Turkey) proposes to do a survey among sections and / or

NMA : What is your section offering on training in rare diseases?

The sections could ask their delegates to survey their own

countries And/ or the NMA could be asked the same questions

Decision: The idea was adopted by the participants and put forward for further elaboration by the bureau

15. Closing of the meeting

The chair thanked all participants for coming and closed the meeting

Addendum

Ad 6- Ulf:

Question on CME accreditation

The chair of EACCME was very pleased that MJC-RUD would offer a possibility to act as assessors of credit applications. However, he could not promise and workload, it is dependent on what items the applicant asks for.

What is needed is that we contact Vassilos with a list of names on persons who could serve as assessors, at least 2.

Ad 8- Ulf:

Conversation with Enrique Terol on 23-10-2017

Dr Terol regrets he has missed to rely on the letter sent to him from the president, and hopes that the discussion today will be helpful for the future.

Three activities involving MJC-RUD and ERNs were identified during the discussion and where immediate action was possible:

1. Dr Terol will invite to a web meeting with the coordinator of all ERNs and prof Casali, the chair of JARC, and the bureau of MJC-RUD for a first round of discussion.
2. We will receive an invitation to participate in a small meeting in Barcelona in February to be able to mingle with the ERN members.
3. An invitation to the ERN leaders meeting in April in Brussels to talk about the MJC and discuss our role.

To do list

Ad 3- Liesbeth

Mail to all members (together with minutes) asking for secretary candidates Ad 4-/7 All :

Adjustment document on MCJ RUD with specifying the importance of guidelines Please all contribute : Liesbeth will revise

Ad 6- Contact members and ask who would like so serve as assessors. Ad -14 All :

Provide questions for sections and NMA on training programs / guidelines on rare diseases. Liesbeth will collect.

Notes taken by Liesbeth Siderius amended by Ulf Kristoffersson

October 29, 2017