



MINUTES

UEMS MJC RUD Meeting

Date and time: October 7, 2022 09:00-11:00				Protocol No 2/2022
Place: Athens, Greece				
Attendees: Bela Melegh Serdar Ceylaner R.O.B. (Reinold) Gans Ambrogio Fassina Jeffrey Bonnici Mark Westwood (briefly) Maeve Durkan (briefly)			Excused: Alexander Bisdorff	
	Point to discuss	Discussion	Decisions	Reference person
1.	Opening of the meeting by BM and approval of agenda	Meeting is opened at 9:00 by BM. This meeting was originally scheduled as an "Annual meeting" but due to limited attendance of the Council Meeting it was agreed to be a side meeting with preparatory functions to the Annual meeting.	Agenda approved	BM
2. 3. 4.	Approval of the Minutes of the 2021 Annual Meeting, Limassol Annual report of the President Annual report of the Treasurer	All participants were sent these documents electronically therefore no detailed discussion was open on any of them.	All documents are approved	BM

5.	EU Exam Issues	<p>In order to make the diagnosis of rare diseases, it should be the main principle that the findings suggestive of rare diseases, that is, rare disease flags, should be taught to specialists in all branches. For this, rare disease flags should be determined by working with all disciplines.</p>	<p>It does not seem possible to know all rare diseases in order to diagnose rare diseases. The most important thing to diagnose is to be able to define algorithms about it. Knowing this algorithm provides the chance of diagnosis in a significant part of the patients. Studies should be carried out to define these algorithms.</p>	SC
		<p>It is very difficult to organize a training that includes all specialties related to rare diseases and to conduct a common exam. ROB and AF expressed their concerns on this issue. BM and SC explained that there will be different types of exams. One is “essentials”, basic knowledge on Rare Diseases. Other types are specialized exams (e.g. ENETS).</p>	<p>BM said that as the ETR has been approved and published and it is proposed to establish an “Enlarged Examination Steering Committee” (EESC) and that the first job of this committee is to determine the content of the trial examination.</p>	BM
		<p>Since people certified in the field of rare diseases are the contact point that organizes the work instead of diagnosing all rare diseases. These persons target will be bringing together all the findings of the patients, especially those with multiple system involvement, and coordinating the interdisciplinary follow-up and</p>	<p>The establishment of multidisciplinary diagnostic departments for undiagnosed patients and the presence of physicians from more than one specialty trained in the field of rare diseases will make significant contributions to the management of diagnosis and treatment processes.</p>	SC

		treatment by these individuals. This service will ensure that the patients receive the right medical service and this will be the most important task of these persons. So basically, this should be an organizational task.	The exam on rare diseases should be about basic knowledge, competencies, and organization rather than a knowledge exam. The necessity of an organization related to rare diseases is clearly seen because the current system does not meet the need.	
6.	Establishment of Enlarged Exam Steering Committee	Connected to the previous agenda point the participants agreed that the trail exam could be the next step.	Participants agreed that the establishment of the EESC is of benefit with authorisation to conduct the trail exam, and in case of success, the first real exam.	
7. 8. 9.	ENETS WG for Laboratory Genetics, ETR for Clinical Laboratory Genetics EBRUD issues, preparatory works	Only 15 minutes were left for these agenda points so these were discussed very briefly.	The participants agreed that those are relevant in the MJC RUD, and should be further discussed at the Annual Meeting of MJC RUD.	
10.	Closing of meeting	Meeting is closed at 11:00		

Minutes taken by: Serdar Ceylaner

AGENDA

MJC RUD – Side meeting
UEMS Council Meeting, Athens
7 October, 2022 – 09:00 – 11:00
Conference Room 2

- 1., Opening, approval of the Agenda
- 2., Approval of the Minutes of the 2021 Annual Meeting, Limassol
- 3., Annual report of the President
- 4., Annual report of the Treasurer
- 5., EU Exam issues
- 6., Establishment of Enlarged Exam Steering Committee
- 7., ENETS
- 8., WG for Laboratory Genetics, ETR for Clinical Laboratory Genetics
- 9., EBRUD issues, preparatory works
- 10., AOB