



UNION EUROPÉENNE DES MÉDECINS SPÉCIALISTES EUROPEAN UNION OF MEDICAL SPECIALISTS

Association internationale sans but lucratif

International non-profit organisation

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UEMS MJC OF RARE & UNDIAGNOSED DISEASES

MINUTES

UEMS MJC of Rare and Undiagnosed Diseases (RUD)

2020-2021 Annual Meeting

Date: October 22, 2021			Protocol No 1/2021	
Place: Limassol / teleconference				
Attendees: Bela Melegh, President Artur Beke Alessandra Renieri, Secretary Domenica Taruscio Joel Ferri Serdar Ceylander Marko Stojanovic Oleg Kvlivdze Risto Lapatto Umut Akyol Josanne Vassallo Malik Maharramli Vesna Kusec Patrick Twomey Ilia Nadareishvili Ipad de Daniel?				
	Point to discuss	Discussion	Decisions	Reference person
1	Opening of the meeting by Bela Melegh and Approval of	Meeting is open at 9:00.	Agenda approved (Supplement 1)	Bela

	agenda			
2	“2018 Minutes”, and “2020 Activity report”	Bela presented “2018 Minutes” (Supplement 2.), and “2020 Activity report” (Attachment 1)	Unanimously approved	Bela
3	The 2019-2020 annual report (President)	Bela presented the Annual Report (Supplement 3 and 4). There is no MJC RUD web at the moment. An MJC RUD membership registry revision is on the way (with Marine Boulard).	Reports unanimously approved. Funds will be requested from UEMS Exec for web and EBRUD launch. We will contact sections which are not represented in the MJC RUD, and ask for delegates.	Bela
4	Annual report of Treasurer	Artur presented the finances annual report (Supplement 5)	Unanimously approved	Artur
5	Undiagnosed Disease Network International (UDNI)	Domenica Taruscio presented the Undiagnosed Disease Network International (UDNI) as Strategic partner of MJC RUD. (Attachment 2) Alessandra proposed that every member as MJC RUD become also member of UDNI	There are already MJC RUD members in UDNI. All the other members are invited to submit the application to UDNI	Domenica
6	Rare diseases of calcified tissues of the head and neck	Joel Ferri presented talk with cases of rare diseases of calcified tissues of the head and neck. Bela proposed to Joel to build a dedicated Working Group (Attachment 3)	Creation of working group unanimously approved. Joel Ferri is the head of this WG	Joel
7	European Board of Rare and Undiagnosed Diseases (EBRUD)	Bela presented a draft (Supplement 6). He already contacted several external partners including Matt Bolz-Johnson and Sharon Ashton	The goal is to prepare the EBRUD materials to the 2022 Council. Funds will be requested for creation	Bela

		from the EURORDIS	of EBRUD and exam.	
8	European Exam in Rare and Undiagnosed Diseases	An exam committee should be created, as part of the MJC RUD and/or EBRUD.	Launch of European Exam preferably in 2022.	Bela
9	AOB	We will proceed with the MJC RUD membership registry housekeeping.	Bela and his secretary will work on this topic with Marine Boulard.	-
10	Closing meeting	Meeting is closed at 11:00		Alessandra

Minutes taken by: Pr. Alessandra Renieri, secretary of MJC RUD

Supplement 1.

MJC RUD combined physical & e-meeting
in association with the
UEMS Council Meeting
Limassol
Friday, 22nd October, 2021.
9:00-11:00

AGENDA

1. Welcome, approval of the Agenda (Bela Melegh)
2. Approval of “2018 Minutes”, and “2020 Activity report” (Alessandra Renieri)
3. Annual reports of the President (2019, and 2020) (Bela Melegh)
4. Annual report of the Treasurer (Artur Beke)
5. Undiagnosed Disease Network International (UDNI) – Strategic partner of MJC RUD (Domenica Taruscio)
6. Rare diseases of calcified tissues of the head and neck (Joel Ferri)
7. European Board of Rare and Undiagnosed Diseases (Béla Melegh)
8. European Exam in Rare and Undiagnosed Diseases (Béla Melegh)
9. AOB

Supplement 2.

Minutes taken by LS & BM

Minutes of UEMS Multidisciplinary Joint Committee of Rare and Undiagnosed Diseases (MJC RUD) board meeting

Date: October 20, 2018; 13:15-14:00			Protocol No 3/2018
Place: Thon Hotel, Brussels			
Attendees: Vassilios Papalois (special guest) <i>UEMS Secretary General</i> Bela Melegh <i>President, Section of Medical Genetics</i> Liesbeth Siderius <i>acting Secretary, Section of Pediatrics</i> Alexandre Bisdorff <i>Section of Neurology</i> Serdar Ceylander <i>Turkish NMA</i> Maeve Durkan <i>Section of Endocrinology</i> Marc Hermans <i>Section of Psychiatry</i> Norbert Mulleneisen <i>Section of Allergy</i> Apologies: Marisa Dias Nursel Celik Basaran Daniela Karall			

	Points	Discussion	Decisions	
1	Opening	Meeting is open at 13:15, with delay.	Due to the delay, the Agenda points 2 & 8 to be discussed mainly electronically, points 4-7 to be discussed together verbatim	BM
2	Agenda point 3	ENETS contacted the UEMS for collaborate in EU exam. A confcall was organized (04.07.18) with A. Pascher, A. Frilling, VP, Lise Carratala, BM. ETR materials were sent along to ENETS partners by LC. IT expert involvement to the MJC RUD suggested	MoU needs to be prepared soon (before their meeting in 30.11.18.) VP will send available MoU forms to BM; a Position (white) paper will be considered on “undiagnosed” topic. MJC RUD will find partners for collaboration via email contact of Sections	VP BM to be named BM
3	Agenda points 4-7	ETR for "Rare Diseases" European Board of Rare Diseases ETR for “Rare adult solid cancers” European Board of Rare adult solid cancers”	All points were considered merit for further development. Call will be circulated amongst Section to identify experts who interested to join; working group(s) will be created	BM
4	Agenda point 8	Joint Action in Rare Cancers (JARC)	Was incorporated in part into the previous point, slides will be circulated later.	BM
5	Agenda point 9	Election postponed (low number of attendees, lack of proxies)	LS remains acting secretary	VP, BM
6	AOB	MD & NM membership application was approved	Monetary support via EU grants will be considered	

Supplement 3.

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

Supplement 4.

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

Supplement 5.

UEMS - Multidisciplinary Joint Committee on Rare and Undiagnosed Diseases /MJC-RUD/

European Union of Medical Specialists

FINANCIAL REPORT 2021

Income - 2021

• <u>Opening balance as of January 1st 2021</u>	<u>0.00 EUR</u>
• -	
• <u>Income:</u>	
• <u>REIMBT EACCME FEES REVIEWS 1ST SEMESTER</u>	<u>200.00 EUR</u>
• <u>/European Accreditation Council for Continuing Medical Education/ 2019 DATE VALEUR : 13/04/2021</u>	
• -	
• <u>REIMBT EACCME FEES REVIEWS 2ST SEMESTER</u>	<u>1,100.00 EUR</u>
• <u>/European Accreditation Council for Continuing Medical Education/ 2019 DATE VALEUR : 13/04/2021</u>	
• -	
• <u>Total income</u>	<u>1,300.00 EUR</u>
• -	

Expenditures - 2021

• <u>Expenditure:</u>	
• <u>UEMS CESMA contribution</u>	- 300.00 EUR
• <u>/Council for European Specialists Medical Assessment/</u>	
•	

• <u>Bank charges</u>	
• REDEVANCE TRIMESTRIELLE	- 20.00 EUR
• REDEVANCE TRIMESTRIELLE	- 30.00 EUR
• REDEVANCE TRIMESTRIELLE	- 30.00 EUR
• REDEVANCE TRIMESTRIELLE	- 30.00 EUR
• INTERETS NETS : DETAILS VOIR ANN	- 0.28 EUR
• INTERETS NETS : DETAILS VOIR ANN	- 0.32 EUR
• INTERETS NETS : DETAILS VOIR ANN	- 0.30 EUR
• <u>Total expenditure</u>	<u>- 410.90 EUR</u>

Closing balance – 2021

• <u>Opening balance as of January 1st 2021</u>	0.00
• <u>Total income</u>	<u>1,300.00</u>
• <u>Total expenditure</u>	<u>- 410.90</u>
• <u>Closing balance as of October 22nd 2021</u>	889.1

Artur Beke

MJC RUD Treasurer

Supplement 6.

European Board of Rare and Undiagnosed Diseases (EBRUD)

Preface:

The main focus of the **European Union of Medical Specialists** (Union Européenne des Médecins Spécialistes – UEMS) is harmonization and improvement of the quality of medical specialist practice in the European Union, which they are trying to achieve by the formulation of a common policy in the field of medical training, continuous medical education, exchanges of trainees between Countries, manpower problems throughout Europe. The UEMS represents more than 50 medical disciplines through various bodies. A European Board as a subgroup was formed in conjunction with the relevant European Society, with the goal of defining European standards of medical education and training. They also contribute to the work of Multidisciplinary Joint Committees (MJC). The European Medical Boards have different board spectrums of goals. Common point is focus is on specific aspects of education. In general the Boards are organized under the umbrella of the UEMS and can be regarded as educational arms of the UEMS.

As the care of rare diseases are multidisciplinary several medical professions, if not all, are involved in the care, therefore, the knowledge base, including the education background should be harmonized by involvement of all medical specialists as major stakeholders in the field. The aim of these medical specialties is to improve the health of patients with rare and undiagnosed diseases and their families by promoting the highest possible standards of care. For this core activities that the EBRUD offers are education, training and certification modalities.

The objectives of EBRUD:

- Recommend the standards required for the training of specialists and the means of maintaining those standards.
- Make proposals for the quality of training and for the syllabus and examine the content and quality of training.
- Recommend the criteria to which the specialist RUD training centers should conform and also conduct site visits of institutions which have agreed to corresponding to these standards

- Make proposals for unifying the training programs to achieve specialist status.
- Ensure that the knowledge and skills of specialists are maintained and updated at regular intervals.
- Develop, with the subspecialties in a system to assess and recognize the quality of training and practice.
- Promote research relevant to rare and undiagnosed diseases.
- Facilitate the exchange and free movements of specialist trainees between training centers throughout Europe to harmonize and improve the quality of training.
- Organize and control the European Board Exam in Rare and Undiagnosed diseases
- Set and manage the CME/CPD of the European Board Diploma/Certificate holders
- Create a CME Registry system for rare disease experts
- Manage webpage of the EBRUD

Mission and Goals:

A unique feature of the EBRUD comes from the nature of the practice achieved in the past decade. Contrary to other medical disciplines, in this field further significant stakeholders are the patient advocacy groups. Therefore, the medical education and the CME/CPD have special aspects since besides the doctors involved in rare disease care, non-medical experts are also involved, with a special significance of the patient advocacy groups who should be involved in the training and patient empowerment. And, vice versa, feedback from them is crucial for continued development. Conclusively, representatives of patient advocacy groups are present. Additional unique feature is the emerging networks involved in specific aspects of rare and undiagnosed diseases, The most important are the European Reference Networks (ERN), which are also present in the EBRUD. While the ERNs are restricted to Europe, further international networks are also involved. In the field of rare and undiagnosed diseases a unique aspect is the special importance of the research, clinical, genomic, and IT. Therefore, professional societies as pillars of research are also included.

How we work

Structure:

-Exec: President, Vice-President, Secretary, Treasurer

National/International Delegates?

The Executive Committee shall be responsible for:

- The management of the daily affairs of the Board, which is the responsibility of the President and the Officers.

- The establishment of the yearly budget and the use to be made of the available funds.
- The preparation of Agendas for Council meetings.
- Ensuring that the Constitution and the By Laws are correctly adhered to.
- Governing body (with professional delegates from all medical specialties involved in RUD).
- Education & Exam Steering Committee:
 - This committee covers all areas of Education and Training for specialist including:
 - Postgraduate Medical Education: general medical training that includes an adult/paediatric/prenatal medicine “internship”, prior to entering competency training in rare disease units.
 - CME/CPD
 - Training Guidelines and syllabus
 - Examinations and qualifications
- International Advisory Board
- Board of Professional Societies: We should agree in list of Societies (open? closed?)
- Board of Patient Advocacy Groups: List of Groups here

Proposed Menu on EBRUD Webpage:

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