



MINUTES

UEMS MJC RUD Side Meeting with presence of the EBRUD delegates

Date and time: October 20, 2023 09:00-11:00				Protocol No 1/2023
Place: Malta, onsite/online, room Carrapechia				
Attendees: Bela Melegh Artur Beke Serdar Ceylaner Alessandra Renieri Vesna Kusec Ambrogio Fassina Domenica Taruscio Jean Calleja Agius Josanne Vassallo Rijk OB Gans Lucas, Matthyssens Ildiko Horváth Encarna Navarro		Excused: Marianna de Visser Antonio Federico Péter Vajda Could not connect: Wouter te Rijdt Marek Bolanowski		
	Point to discuss	Discussion	Decisions	Reference person
1.	Opening of the meeting by BM and approval of agenda	Meeting is opened at 09:00 by BM.	Agenda approved.	BM
2.	Approval of the Minutes of the 2022 Annual Meeting	BM outlined the minutes from the 2022 Annual Meeting, which one was an onlie meetng.	Minutes approved	BM
3.	Annual report of the President (year 2022)	BM outlined the Annual Report of the President point by point.	Annual Report approved	BM
4.	Annual report of the Treasurer (year 2022)	AB presented the Annual Report.	Annual Report approved	AB

5.	Progress in partnering	<p>Draft MoU with ESHG (European Society of Human Genetics),</p> <p>Draft MoU with EURO-NMD (European Reference Network of Neuromuscular Diseases),</p> <p>Draft MoU with ERN-RND (European Reference Network of Rare Neuromuscular Diseases).</p>	<p>Approved</p> <p>Approved</p> <p>Approved</p> <p>All drafts will be sent to Bertrand Daval for legal and formal control.</p>	BM
6.	European Board of Rare and Undiagnosed Diseases (EBRUD) issues	The electronic nomination and election procedure of the EBRUD Bureau (Exec) has been successfully completed under the management and supervision of UEMS Coordination.	The newly elected Bureau will proceed with definition, identification, and sharing/ of MJC RUD and EBRUD tasks.	BM
7.	Progress in the European Board Exam in Essentials of Rare and Undiagnosed Diseases	<p>It will be a competence (or top up) exam, instead of an exit exam.</p> <p>The certificate of competence to be awarded will be called: 'Essentials in Rare and Undiagnosed Disease'. It was clarified that the exam will be exclusively for medical doctors and /or specialists and hence, the questions have to be set by medical doctors hailing from different specialties.</p> <p>The EESC already has been set, according to the recommendation of Bartrad Daval, a vote is recommended.</p> <p>There needs to be the set up of a 'Question writing</p>	<p>The links to the current information related to rare and undiagnosed diseases which are already present on the UEMS website will be circulated by BM.</p> <p>It needs to be clarified who the candidates will be (who will be sitting for the exam), and what they need to study in order to pass the exam (the knowledge base vs identifying the red flags of a rare disease and the clinical reasoning). A team led by Prof Serdar Ceylaner will need to write a leaflet/book with as a reference of the whole list of topics for students to refer to when preparing for the exam.</p>	BM, JV, SC

		group' or 'groups' for the different sections; a 'Standard Setting Group, etc prior to the actual trial exam. A company needs to be identified in order to be able to run the logistics of the exam. A timeline for all of this needs to be agreed on, with named individuals assigned to each group to have set guidelines and deadlines to adhere to.	This list should include the red flags of rare diseases. To be completed by 31 December, 2023.	
8.	AOB	In the past annual meeting the chore of "Laboratory Genetics" has been postponed on the request of the Section of Laboratory Medicine. A letter was sent by them (included in the Minutes of 2022 MJC RZD meeting).	In year of 2024 this issue will be discussed and progress should be achieved.	BM
9.	Closing of meeting	Meeting is closed at 11:10		

Minutes taken by JCA, SC and BM

AGENDA

MJC RUD – Side meeting
UEMS Council Meeting, Malta
October 20, 2023
09:00 – 11:00
room Carrapechia

1., Opening, approval of the Agenda

2., Approval of Minutes of MJC RUD Annual Meeting 2022

3., Annual report of President

4., Annual report of Treasurer

5., Progress in partnering

MoU with ESHG (European Society of Human Genetics), EURO-NMD (European Reference Network of Neuromuscular Diseases), ERN-RND (European Reference Network of Rare Neuromuscular Diseases). Draft circulated.

6., EBRUD launch

The electronic nomination and election procedure of the EBRUD Bureau (EXEC) has been successfully completed under the management and supervision of UEMS Coordination. The newly elected Bureau will proceed with definition and sharing of MJC RUD and EBRUD tasks.

7., Progress in the European Board Exam in Essentials of Rare and Undiagnosed Diseases

Trial Exam, acting Enlarged Exam Steering Committee (EESC) under the umbrella of the EBRUD, with authorization of Exam coordination supervision.

8., AOB



MINUTES

UEMS MJC RUD Annual Meeting

Date and time: November 15, 2022 17:00-19:00				Protocol No 3/2022
Place: online				
Attendees: Bela Melegh Artur Beke Serdar Ceylaner Alessandra Renieri Ambrogio Fassina Joel Ferri Pat Twomey Domenica Taruscio John Firth Olle Hollertz George Petrikkos Eva Tienssu Janson Daniel Hohl Marek Bolanowski Jean Calleja Agius Anna Nikulina Oleg Kvlividze Josanne Vassallo Leah Matthews		Excused: Maeve Durkan Marek Bolanowski Rijk OB Gans Risto Lapatto		
	Point to discuss	Discussion	Decisions	Reference person
1.	Opening of the meeting by BM and approval of agenda	Meeting is opened at 17:00 by BM. PT requested to postpone point 9., because it was discussed shortly before the MJC RUD meeting at the Section of Laboratory Medicine.	Agenda approved. BM agreed and asked that the supporting documents like Explanatory Notes from the Section of Laboratory Medicine be provided later on. *	BM

2.	Approval of the Minutes of the 2021 Annual Meeting, Limassol	BM outlined the minutes from the 2021 Annual Meeting in Limassol.	Minutes approved	BM
3.	Annual report of the President (year 2021)	BM outlined the Annual Report of the President.	Annual Report approved	BM
4.	Annual report of the Treasurer (year 2021)	AB presented slides on the Annual Report.	Annual Report approved	AB
5.	EU Exam “Fundamentals of Rare and Undiagnosed Diseases” issues	To proceed with this task, the following steps are proposed: - Description of the exam (volunteers are needed to constitute a 10-20 pages long text) - establishment of Enlarged Exam Steering Committee with the complete and exclusive authorization of the coordination and management of all exam tasks, with a 4 year long mandate (starting from January 2023). - organization of a remote (online) trial exam in early 2023	Approved Approved Approved	BM
6.	European Neuroendocrine Tumor Society (ENETS)	Presentation by ENETS	BM congratulated on behalf of MCJ RUD and offered his further support.	ETJ, LM
7.	WG for Rare Diseases of Bone Tissues of the Head (WGRDBTH)	BM presented the letter of OMFS section.	After extensive discussion the proposal of OMFS was unanimously approved and JF was elected as head of WG of RDBTH.	BM
8.	European Board of Rare and Undiagnosed Diseases (EBRUD) issues	The delegates already received the letter circulated amongst the UEMS bodies calling for nominations to the EBRUD.	After nominations the MJC RUD will continue with EBRUD preparation works according to the already approved organizational chart.	BM

9.	WG for Laboratory Genetics, ETR for Clinical Laboratory Genetics	Postponed by the request from PT.	Request approved. Waiting for explanatory notes. *	BM
10.	CME/CPD	Preliminary draft by BM.	Further discussion is needed.	BM
11.	AOB	-		
12.	Closing of meeting	Meeting is closed at 19:00		

* Letter from Section of Laboratory Medicine by Nov. 18, 2022 received electronically on the same day (attached).

Minutes taken by BM

AGENDA

with supplementary notes

Annual Meeting of MJC RUD

15 November, 2022

online meeting, 17.00 – 19.00 hrs

1., Opening, approval of the Agenda

2., Approval of the Minutes of the 2021 Annual Meeting, Limassol

3., Annual report of the President (year 2021)

4., Annual report of the Treasurer (year 2021)

5., EU Exam “Fundamentals of Rare and Undiagnosed Diseases” issues

To proceed with this task, the following steps are proposed:

- Description of the exam (volunteers are needed to constitute a 10-20 pages long text)
- establishment of Enlarged Exam Steering Committee with the complete and exclusive authorization of the coordination and management of all exam tasks, with a 4 year long mandate (starting from January 2023).
- organization of a remote (online) trial exam in early 2023

6., European Neuroendocrine Tumor Society (ENETS)

- a representative is invited to present the current status

7., WG for Rare Diseases of Bone Tissues of the Head (WGRDBTH)

- letter of OMFS Section; due to personal changes we have to reshuffle the current WG RDBTH according to the proposal of the Bureau of the OMFS Section

8., European Board of Rare and Undiagnosed Diseases (EBRUD) issues

- preparatory works are on the way, letter to the UEMS Bodies

9., WG for Laboratory Genetics, ETR for Clinical Laboratory Genetics

- proposal for the creation of this new WG, with the long-term goal of the construction of an ETR

10., CME/CPD

- new approach is proposed: development of a system for EU Exam holders

11., AOB

MINUTES
 UEMS MJC of Rare and Undiagnosed Diseases (RUD)
 2020-2021 Annual Meeting Limassol

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 Kvlividze 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 agenda	Meeting is open at 9:00.	Agenda approved (Supplement 1)	Bela
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 from the EURORDIS	The goal is to prepare the EBRUD materials to the 2022 Council. Funds will be requested for creation of EBRUD and exam.	Bela
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

Annual Report of the President – 2021

10 October, 2022

The calendar year of 2021 was the 5th full year in the history of the MJC RUD. The continuing Covid 19 pandemic strongly influenced our activity, however, the activity improved and we had a productive year. In short, the calendar year of 2021 was about the organizations and preparatory works.

Membership

According to the last control, we had a total of 47 members from 27 Sections (OMFS, IM, Ophthalmology, Paediatrics, Psychiatry, Rheumatology, Medical Genetics, Neurology, Paediatric Surgery, Pharmacology, and Rehabilitation). They together were from 21 countries, and 3 additional were non EU Nations (Armenia, Georgia, Turkey). 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. The process of “housekeeping” is still on the way with the assistance of the UEMS Coordination.

The Bureau

Electronic votes were organized by the Coordination in 2019-20; taken together, Dr. Domenica Taruscio was elected as vice-president, and Dr. Artur Beke was elected as treasurer, the president was re-elected. All 4 yrs office terms were agreed to start in 2021 January lasting till December of 2024. Thereby the Bureau consists of the president, secretary, treasurer, and 2 vice presidents with office terms till December of 2024.

MJC RUD Meetings

There was an onsite/e-remote official membership meeting in association of the Limassol Council Meeting (22 October, 2021), which was a combined meeting for years 2020-2021. Besides this, well balanced activity was conducted also via emails.

Main focus in 2020 and after

As the 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) in 2019, we focused on organization of future exam, and focused on the possible extension of training activities. Thus, the priorities included the preparatory phase of the European Board of Rare and Undiagnosed Diseases (EBRUD) and then the European Exam in fundamentals of rare diseases.

Working Group for Rare Diseases of Calcified Tissues of Head (WG RDCTH) was established with coordination of Joel Ferri from OMFS Section.

Besides this, intensive partnering was initiated with the EURORDIS.

Home page

Historically, our 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 and the new SMG Bureau suspended this

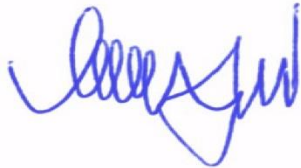
courtesy service. Thanks to the help of the UMES Exec, we reorganized the website in 2021, and we have a new profile (<https://mjcrud-uems.pt.hu>).

Finances

Thanks to the aid of the UEMS Exec, we received a 7,000 Euros refundable loan from the UEMS budget. This sum, and the income from the event reviews, resulted in a closing balance of 7,576.97 Euros in 31 December, 2021, we already paid 300 Euros CESMA membership contribution for 2022. The president evaluated 7 life events for the CESMA.

Participation in other activities

Lecture was presented at the 10th meeting of Undiagnosed Network International (UDNI) summarizing our main goals. The president participated in the work of the CESMA, and continued with the EACCME "Training the reviewers" working group.



Dr. Béla Melegh
professor
MJC RUD President

ANNUAL REPORT OF TREASURER

UEMS MULTIDISCIPLINARY JOINT COMMITTEE ON RARE AND UNDIAGNOSED DISEASES

FINANCIAL STATEMENT SUMMARY FOR CALENDAR YEAR 2021

Opening balance as of January 1st 2021 **0.00 EUR**

Income:

EACCME REIMBT FEES REVIEWS 1ST SEMESTER 200.00 EUR
/European Accreditation Council for Continuing Medical Education/
2019 DATE VALEUR : 13/04/2021

EACCME REIMBT FEES REVIEWS 2ST SEMESTER 1,100.00 EUR
/European Accreditation Council for Continuing Medical Education/
2019 DATE VALEUR : 13/04/2021

EACCME REIMBT FEES REVIEWS FEES 2ND SEM 20 200.00 EUR
European Accreditation Council for Continuing Medical Education/
DATE VALEUR : 16/11/2021

EACCME REIMBT FEES REVIEWS FEES 1ST SEM 20 450.00 EUR
European Accreditation Council for Continuing Medical Education/
DATE VALEUR : 16/11/2021

UEMS LOAN 2021 7,000.00 EUR
DATE VALEUR : 30/11/2021

Total income **8,950.00 EUR**

Expenditure:

UEMS CESMA contribution - 300.00 EUR
/Council for European Specialists Medical Assessment/

UEMS Council Meeting - Limassol - 2021.10.22 - 962,13 EUR
(Reimbursement Bela Melegh)

Bank charges

REDEVANCE TRIMESTRIELLE - 20.00 EUR

REDEVANCE TRIMESTRIELLE - 30.00 EUR

REDEVANCE TRIMESTRIELLE - 30.00 EUR

13

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

Total expenditure - **1,373.03 EUR**

Closing balance as of December 31st 2021 **7,576.97 EUR**

Prepared by Artur Beke MD PhD

Treasurer, Multidisciplinary Joint Committee on Rare and Undiagnosed Diseases

31.12.2021

Letter from OMFS Bureau:

To

Dr. Melegh Béla

melegh.bela@pte.hu

MJC Rare and Undiagnosed Diseases (RUD)

October 24, 2022

Dear Colleague,

I am writing to you regarding the benefit to UEMS and to European patients of our friend and colleague Joel Ferri being able to continue his excellent work as the OMFS Section representative on the MJC RUD.

Dr Ferri is no longer a delegate to the OMFS Section, but we would be grateful if you could use your ability within the UEMS Rules of Procedure to invite him to be an observer on the MJC RUD.

If you confirm that you are happy to co-opt Dr Ferri onto the MJC RUD, we will invite him to attend the OMFS Section as a representative of the MJC RUD and an observer to the OMFS Section.

Patrick Magennis
President OMFS Section

Hans-Peter Ulrich
Secretary/Treasurer OMFS Section

To Presidents & Secretaries UEMS Specialist Sections, European Boards, MJC, Divisions

Dear Colleagues,

15 November, 2022

As you might be aware, at the UEMS Council of 29-30. April of 2022, creation of the European Board of Rare and Undiagnosed Diseases (EBRUD) was approved and the MJC RUD was thus authorized to proceed with the organization of the EBRUD, according to the RoP of the UEMS.

The MJC RUD team consulted the UEMS Enlarged Executive and already initiated the preparatory works.

It is an essential element in our Statutes and RoP, that when a European Board creation is approved by the UEMS Council, the MJC has to inform its MJC members (Sections and other bodies) and each interested UEMS body (Section, MJC) may nominate a delegate to the European Board. This nomination is not restricted to the Section's delegate to the MJC. Furthermore, with regard to the composition of the European Board: „Each delegation to a Board shall consist in 2 members, one from the Section and one from the recognized academic or Scientific Society of the country“, provided that the nomination conditions apply to each member.

During the preparatory works that have been performed so far, we have received nominations from Sections, but none from scientific societies yet. We would highly appreciate if you could consider this information and send your nominations till 22 December, 2022.

On behalf of the MJC RUD I thank you for your consideration, and look forward to hearing your nominations.

Yours,



Béla Melegh
MJC RUD President

Prof. Borut Peterlin
President of ESHG

15 November, 2022

Dear Mr. President,
Dear Borut,

I'm contacting you on behalf of the Multidisciplinary Joint Committee of Rare and Undiagnosed Diseases (MJC RUD) of the European Union of Medical Specialties (UEMS). Here I would like to initiate a discussion in two related, but still separate issues.

The first is to initiate a partnership in the MJC RUD system of European assessment in rare and undiagnosed diseases, which is under development, with an ultimate goal of launch a "European Exam in Essentials of Rare and Undiagnosed Diseases". Luckily, I do not have to go too much into the details, since you and the ESHG Exec members are familiar with the UEMS European Exams: we already collaborated in the launch of European Exam in Medical Genetics and Genomics, which was introduced under my presidency of Section of Medical Genetics (SMG) in 2018. In this sequence the ESHG could remain a crucial partner of us. The prestige of the certificate was hugely increased by the fact that the ESHG logo is on the diploma, and the statement "This certificate is recognized as specialist certification in medical genetics by the European Society of Human Genetics" is printed on it (copy of original is attached). Essentially this is the same partnership we propose now for the examination in RUD. To solve the possible worries and concerns, I have to underline here again, that the participation of the ESHG would not include any liability consequence, as it wasn't there in the SMG exam as well.

The core rare diseases exam would be something new. At the moment no such qualification exists in any country, but in some nations authorities do work on it, like Australia, UK, and Lithuania. In our exam a quite prestigious exam committee already supports the goals, like Domenica Taruscio, Wendy van Zelst Stams, Bruce Korf, William Gahl, Gareth Baynam, are prominent names from the long list.

The second issue is also related to the rare disease tasks. At the UEMS Council of 29-30. April of 2022, creation of the European Board of Rare and Undiagnosed Diseases (EBRUD) was approved, which means in UEMS terms that this approval authorized the MJC RUD to proceed with the organization of the EBRUD, according to the RoP of the UEMS. The UEMS European Boards are working groups of the UEMS Bodies but it is of utmost importance and value that recognized academic or scientific societies participate in their work by delegating representatives. Due to the nature of the current and future MJC RUD activity, presence of the ESHG would be pivotal.

On behalf of the MJC RUD I thank you for your consideration, and look forward to hearing your decision.

Yours,



Béla Melegh
MJC RUD President



EUROPEAN UNION of MEDICAL SPECIALISTS
Specialist Section of Laboratory Medicine/Medical Biopathology

www.uems-slm.org

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18.11.2022

Dear Bela,

The Section of Laboratory Medicine noted that on the agenda of the online Annual Meeting of MJC RUD 15 November, 2022 the topic of

“WG for Laboratory Genetics, ETR for Clinical Laboratory Genetics - proposal for creation this new WG, with the long-term goal of construction of an ETR”

Laboratory Genetics has been part of the ETR for Laboratory Medicine since its inception. The Section of Laboratory Medicine further noted that the Section has not received any information regarding this proposal from MJC RUD despite this long history. The unilateral proposal of the creation of a separate ETR for Clinical Laboratory Genetics goes against this long history of the Section of Laboratory Medicine's ETR.

Laboratory Genetics continues to be heavily grounded in Laboratory Medicine and this was unanimously agreed by our Section delegates as recently as 5th November 2022. Although no concerns have been expressed to us that the existence of the ETRs for Laboratory Medicine and for other specialities could potentially cause confusion in individual countries, (since our last ETR was approved) there has been on our initiative, increased co-operation between the Section of Laboratory Medicine and other Sections concerning areas of mutual interest. I am happy to report that there is a constructive and collaborative working relationship between the Section of Laboratory Medicine and other Sections. I have no doubt that this will continue as our respective ETRs are updated.

The creation of an extra ETR under the MJC RUD does not seem to be necessary. More importantly, this has the potential to cause confusion in individual countries especially concerning the role of medical specialists in Laboratory Genetics.

As stated at the MJC RUD 15 November meeting, we noted that this topic is not urgent and were grateful that you acquiesced to our request to postpone this topic from the agenda with a view to discussing this topic offline. In advance of any such meeting, I would be grateful if you could pass on relevant information to myself and relevant stakeholders copied in so that we can prepare for the meeting in a colligate fashion.

Yours sincerely

Stylianos Chatzipanagiotou
Section Secretary

Patrick Twomey
Section President



Annual Report of the President – 2022

10 October, 2023

The calendar year of 2022 was the 6th full year in the history of the MJC RUD. The Covid pandemic still influenced our activity, however, the activity was satisfactory and we had a productive year. The calendar year of 2021 was about continuing the organizations and preparatory works.

Membership

According to the last control, we had a total of 52 members from 27 Sections (OMFS, IM, Ophthalmology, Paediatrics, Psychiatry, Pulmonology, Rheumatology, Medical Genetics, Neurology, Paediatric Surgery, Pharmacology, and Rehabilitation). They together were from 21 countries, and 3 additional were non EU Nations (Armenia, Georgia, Turkey, Ukraine). The following NMAs sent directly delegates: Austria, Georgia, Greece, Hungary, Norway, The Netherlands, Spain and Turkey. There were resignations, and indirect evidence suggest that some of the members on the list are not active. Therefore, the process of “housekeeping” is still on the way with the assistance of the UEMS Coordination.

The Bureau

The Bureau (Exec) is the same, it consists of the president (Bela Meleg), secretary (Alessandra Renieri), treasurer (Artur Beke), and 2 vice presidents (Domenica Taruscio and Serdar Ceylaner) with office terms till 31th December, 2024. At this point it looks worthwhile to mention that numerous members of us are active members of different UEMS bodies, which is an advantageous for our activity.

MJC RUD Meetings

There was an e-remote official membership meeting (Annual Membership meeting November 15, 2022 17:00-19:00), while the President participated at the spring UEMS Council. Besides these, reasonable activity has been conducted also via emails.

Main focus in 2022 and beyond

The 2022 spring UEMS Council approved the launch of the European Board of Rare and Undiagnosed Diseases (EBRUD). In the MJC RUD the preparatory works for the European Board Exam in Essentials of Rare and Undiagnosed Diseases had been extended. Acting Enlarged Exam Steering Committee (EESC) has been established with a 4 years appointment.

MoU was signed with the EURORDIS, and intensive partnering was initiated with ERN RND, ERN EURO-NMD, and ESHG (European Society of Human Genetics).

Home page

Thanks to the help of the UMES Exec, we reorganized the website in 2021, and we have a new profile (<https://mjcrud-uems.pt.hu>), which has been updated periodically.

Finances

The monetary balance is positive (we have 4,990.14 Euros on the account of the MJC RUD).

The president evaluated 7 life events for the CESMA.

Participation in other activities

Lecture was presented at the 11th meeting of Undiagnosed Network International (UDNI) summarizing our main goals. The president participated in the work of the CESMA, and also continued with the EACCME "Training the reviewers" working group.



Dr. Béla Melegh
professor
MJC RUD President

UEMS MULTIDISCIPLINARY JOINT COMMITTEE ON RARE AND
UNDIAGNOSED DISEASES

FINANCIAL STATEMENT SUMMARY FOR CALENDAR YEAR 2022

Opening balance as of January 1st 2022 **7,576.97 EUR**

Income:

Total income **0.00 EUR**

Expenditure:

Reimbursement

28/12/2022 - - 639,85EUR
Reimbursement-UEMS meeting-Athens-Bela Melegh

23/09/2022 -989,03EUR
Reimbursement -CESMA meeting-Venice-Bela Melegh

22/09/2022 -530,03 EUR
Reimbursement-UEMS Council Meeting-Brussels-Bela Melegh

UEMS CESMA contribution

22/09/2022 -300 EUR
UEMS/CESMA CESMA contribution MJC RUD

Bank charges

01/10/2022 -30 EUR
REDEVANCE TRIMESTRIELLE

01/07/2022 -30 EUR
REDEVANCE TRIMESTRIELLE

01/04/2022 -30 EUR
REDEVANCE TRIMESTRIELLE

20/02/2022 -7,92 EUR
UEMS AISBL Neg interest

01/01/2022
REDEVANCE TRIMESTRIELLE

-30 EUR

Total expenditure **- 2,586.83 EUR**

Closing balance as of December 31st 2022 **4,990.14 EUR**

Prepared by Artur Beke MD PhD
Treasurer, Multidisciplinary Joint Committee on Rare and Undiagnosed Diseases
31.12.2022



**UNION EUROPÉENNE DES MÉDECINS
SPÉCIALISTES
EUROPEAN UNION OF MEDICAL
SPECIALISTS**

Association internationale sans but lucratif International non-profit organisation

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MEMORANDUM OF UNDERSTANDING

BETWEEN:

(1) **UEMS (European Union of Medical Specialists)**; an international non-for-profit organization incorporated under the laws of Belgium, having its registered seat at 24 rue de l'Industrie, 1040 Brussels – Belgium, acting through its Multidisciplinary Joint Committee of Rare and Undiagnosed Diseases [MJC RUD], hereby validly represented by Vassilios Papalois, UEMS President, Joao Grenho, UEMS Secretary General, and Béla Melegh MJC RUD President, Alessandra Renieri, MJC RUD Secretary, Domenica Taruscio, MJC RUD Vice-President,

Hereafter: "UEMS"

and

(2) **ERN-RND** The European Reference Network for Rare Neurological Diseases (ERN-RND) aims to address the unmet needs of more than 500,000 people living with RNDs in Europe. 60% of those are still undiagnosed. Through coordination and knowledge transfer, ERN-RND shall establish a patient-centred network to address the needs of patients with RND of all age groups, with or without a definite diagnosis, by implementing an infrastructure for diagnosis, evidence-based management, treatment and collection of patient data. The ERN-RND Board is the main decision taking body of ERN-RND. The board sets the strategy for the network. The board is chaired by the network co-ordinator. The membership of the board includes the individual HCP leads (or their nominated deputies). The board meets twice a year. The ERN-RND coordination team are based in Tübingen, Germany. ERN-RND coordinators are Holm Graessner and Ludger Schöls.

Hereafter: "ERN-RND"

PRESIDENT: VASSILIOS PAPALOIS
TREASURER: OTHMAR HAAS

SECRETARY-GENERAL: JOAO GRENHO
LIAISON OFFICER: ROMUALD KRAJEWSKI

UNION EUROPÉENNE DES MÉDECINS SPÉCIALISTES EUROPEAN UNION OF MEDICAL SPECIALISTS

Association internationale sans but lucratif – International non-profit organisation

The parties sub (1) and (2) shall hereafter be referred to individually as a “Party” and collectively as the “Parties”.

RECITALS

The UEMS and ERN-RND are active in areas relevant to the quality of medical specialist practice in rare and undiagnosed diseases in Europe primarily, but with global holistic availability and to the quality of care for the benefit of patients around the world. The Parties are willing to create a partnership that will promote and facilitate their activities in this area.

The overall goal of collaboration and cooperation is to define joint actions, to achieve the best possible outcomes and to increase visibility of both parties.

The parties seek through this Memorandum of Understanding (“MoU”) to define their partnership, to explore and to develop new opportunities in accordance with their objectives and competence. Through this MoU, the Parties also aim to establish an efficient and transparent communication between them.

THE PARTIES DECLARE THAT

1. SCOPE

This MoU outlines the principles of collaboration between the UEMS and ERN-RND.

2. INTENTION OF THE PARTIES

The Parties acknowledge that this MoU does not, and is not meant to, constitute a legally binding agreement between them. Whenever an activity undertaken by both Parties would require a formal legal framework Parties will conclude a formal, legally binding agreement.

The non-binding relationship between the UEMS and ERN-RND governed by this MoU is that of independent contractors. Nothing contained in this document will be construed as constituting any other relationship between the Parties.

This MoU does not prevent or limit ERN-RND or UEMS to enter agreements with other parties. Both Parties declare that they will not enter agreements that would jeopardize or invalidate this MoU and, whenever reasonable doubt would arise as to whether a new agreement is likely to be in conflict with this MoU, the Parties will communicate and strive to resolve outstanding issues.

UNION EUROPÉENNE DES MÉDECINS SPÉCIALISTES EUROPEAN UNION OF MEDICAL SPECIALISTS

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3. INTERNAL POLICIES

Subject to the terms of this MoU, the implementation and pursuit of the goals, objectives, conditions and terms of this collaboration will be carried out in accordance with the internal policies and procedures of each Party.

4. SCOPE OF COMPETENCES AND ROLES

a. ERN-RND

The European Reference Network for Rare Neurological Diseases (ERN- RND) includes a group of 6 neurological diseases but hopes to expand over time in terms of the diseases it covers and in terms of EU countries involved. These 6 Disease Groups (DGs) gather the respective experts from all ERN-RND member hospitals. They work on DG specific topics such as care standards, specific dissemination of disease knowledge, etc. Each DG is lead by several coordinators.

The disease groups are the following:

- Cerebellar Ataxias and Hereditary Spastic Paraplegias
- Chorea and Huntington’s disease
- Dystonias, Paroxysmal disorders and Neurodegeneration with Brain Iron Accumulation (NBIA)
- Frontotemporal Dementia
- Leukodystrophies
- Atypical Parkinsonism syndromes: Genetic PD, Multiple System Atrophy, Progressive Supranuclear Palsy, Corticobasal degeneration

The goals of ERN-RND include:

- To significantly increase the overall percentage of RND patients with a final diagnosis
- To improve and harmonise care of RND patients across the EU
- To develop, share and implement care pathways and guidelines for all RND groups represented in ERN-RND
- To create, develop and enhance constituents’ capacity to design, implement and supervise RND training, education and capacity building measures at the level of member states and of the network

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- To develop a comprehensive and data based European RND cohort to better understand these conditions and thus improve their management and help developing and testing treatments
- To define minimum quality and interoperability criteria for RND registries

b. UEMS

According to its articles of association, the UEMS objectives are to promote the harmonization of training standards for specialist physicians within the European Union and to promote free movement of specialist doctors within the European Union. The UEMS is independent from medical industry in order to assure unbiased position in areas of medical politics and in accreditation of CME.

The key activities of the UEMS include:

- Political lobbying (European Commission, Parliament, Support of NMAs)
- Standard setting for specialist training and practice
- Accreditation of continuing medical education (CME) and continuing professional development (CPD)
- Control of exam procedures

The UEMS members are delegated by 41 National Medical Associations. Specialist Sections, their Divisions and Boards, and Multidisciplinary Joint Committees are UEMS bodies, created to promote and defend the interests of medical specialists in their respective fields and to improve the quality of medical specialist training and practice at the European level.

5. MUTUAL RECOGNITION

Each Party acknowledges the competences of the other, according to its articles of association.

Each Party acknowledges that the other is an essential partner in the development and improvement of the quality of **medical specialist practice of diagnosis, treatment, education and aftercare of the rare and undiagnosed patients and specialists involved in their care**. Parties recognize that their continued collaboration should be a crucial and integral element to the future success of both organizations and their members.

6. AREAS OF COOPERATION BETWEEN THE UEMS AND THE ERN-RND

UNION EUROPÉENNE DES MÉDECINS SPÉCIALISTES EUROPEAN UNION OF MEDICAL SPECIALISTS

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Parties undertake to collaborate in order to achieve the objectives of mutual interest. The areas of collaboration between the UEMS and ERN-RND can include, but shall not be limited to:

- Elaboration of European, and worldwide specialist training curriculum
- Partnering in launch of European Board of Rare and Undiagnosed Diseases (EBRUD)
- Organisation of specialist European examinations available for worldwide candidates
- Organisation of visitation programs
- Development and promotion of high quality, unbiased CME/CPD
- Setting European, and worldwide standards of specialist practice
- Explore accreditation of training programmes and other educational activities such as conferences or webinars focused on the development of expertise in rare diseases
- Provision of joint opinion and statements to the EU/worldwide institutions
- Advocacy action including provision of joint opinion and statements to the EU institutions
- Networking between specialties. Engagement with both trainee representatives, medical experts, researchers and patient organizations and promote meaningful patient-professional-partnership.

The UEMS and ERN-RND commit to working in close cooperation and to actively exchange information that is of common interest and/or might be of significance to both organizations and their members.

Parties recognize that:

- Each Party is a key partner in areas of collaboration described in this document
- ERN-RND concentrates on organization and networks of patients, researchers and experts, to engage in scientific research, development of practice guidelines and standards
- UEMS expertise concentrates on accreditation of CME/CPD, elaboration of Training Requirements and curricula and organization of European Examinations

Parties agree to involve the other Party when elaborating major policy documents at the earliest possible stage of the process in order to receive its input.

7. EUROPEAN BOARD

RUE DE L'INDUSTRIE, 24
BE- 1040 BRUSSELS

www.uems.eu

T +32 2 649 51 64

F +32 2 640 37 30

coordination@uems.eu; ceo@uems.eu

UNION EUROPÉENNE DES MÉDECINS SPÉCIALISTES EUROPEAN UNION OF MEDICAL SPECIALISTS

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The UEMS and ERN-RND acknowledge that the MJC RUD is the framework for cooperation and the forum for discussion between representatives of both Parties. ERN-RND recognizes that MJC RUD is a UEMS body and should follow the rules of the UEMS described in its Statutes and Rules of Procedures.

The Parties will closely cooperate to establish satisfactory representation of each Party in MJC RUD.

The UEMS Boards are education arms of the UEMS entries. The parties aware that the UEMS, and UEMS MJC RUD goals include establishment and launch of the EBRUD. The ERN-RND hereby join to this endeavor, according to the spirit and basic principles of the present MoU.

8. COMMUNICATION

The MJC RUD and the EBRUD, when it will be launched, will be in charge of communication with ERN-RND in all matters regarding areas of cooperation defined in this MoU, including communications to the UEMS Executive, other UEMS bodies and to UEMS constituency. This MoU does not change the UEMS representation rules described in statutory documents or waive information and approval duties of MJC RUD.

ERN-RND will communicate with MJC RUD in all matters regarding areas of cooperation defined in this MoU.

ERN-RND and the MJC RUD will each appoint a person for all contacts with the other party. Should there be a change in each Party's contact person, the partner shall inform each other as soon as possible.

Both parties will provide a link on their website to the other's website.

a. Official announcement

An official announcement of the present agreement will be made on both Parties websites as a common statement by the UEMS and ERN-RND after signature of the agreement. The statement will be also circulated to both Parties constituency.

9. REPRESENTATION

The President of ERN-RND or an appointed representative of ERN-RND is invited to take part to the UEMS MJC RUD's executive meetings.

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Likewise, the President of the UEMS Section and Secretary or another representative of the MJC RUD is invited to take part in meetings of ERN-RND conferences, workshops or agreed meetings.

10. FUNDING

This MoU does not include the exchange of funds between parties.

11. MODIFICATION

This MoU can be modified or amended only by a writing signed by both parties.

12. TERM AND TERMINATION

This MoU is concluded for an indefinite period.

13. EFFECTIVITY

This MoU is effective immediately upon signature of all parties here to.

Date: 3rd March 2022



Vassilios Papalois
UEMS President

Holm Graessner
ERN-RND Coordinator



João Grenho
UEMS Secretary General

Ludger Schöls
ERN-RND Coordinator



Béla Melegh

XY
Position at ERN-RND

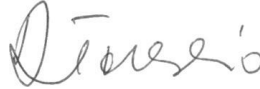
**UNION EUROPÉENNE DES MÉDECINS SPÉCIALISTES
EUROPEAN UNION OF MEDICAL SPECIALISTS**

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President of MJC RUD



Alessandra Renieri
Secretary of MJC RUD



Domenica Taruscio
Vice-President of MJC RUD



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www.uems.eu

T +32 2 649 51 64

F +32 2 640 37 30

coordination@uems.eu; ceo@uems.eu

MEMORANDUM OF UNDERSTANDING

BETWEEN:

(1) UEMS (European Union of Medical Specialists); an international non-for-profit organization incorporated under the laws of Belgium, having its registered seat at 24 rue de l'Industrie, 1040 Brussels – Belgium, acting through its Multidisciplinary Joint Committee of Rare and Undiagnosed Diseases [MJC RUD], hereby validly represented by Vassilios Papalois, UEMS President, Joao Grenho, UEMS Secretary General, and Béla Melegh MJC RUD President, Alessandra Renieri, MJC RUD Secretary, Domenica Taruscio, MJC RUD Vice-President,

Hereafter: "UEMS"

and

(2) The European Society of Human Genetics (ESHG) and has its seat in Vienna, Austria. Registry number ZVR 1086789529, represented by Valérie Cormier Daire, ESHG President, William Newman ESHG President Elect, Borut Peterlin, ESHG Vice-President, Carla Oliveira, ESHG Secretary General, Karin Witzl, ESHG Deputy Secretary General, Gunnar Houge, ESHG Treasurer, Jerome del Picchia, ESHG Executive Officer.

Hereafter: "ESHG"

The parties sub (1) and (2) shall hereafter be referred to individually as a "Party" and collectively as the "Parties".

PRESIDENT: VASSILIOS PAPALOIS
TREASURER: OTHMAR HAAS

SECRETARY-GENERAL: JOAO GRENHO
LIAISON OFFICER: ROMUALD KRAJEWSKI

UNION EUROPÉENNE DES MÉDECINS SPÉCIALISTES EUROPEAN UNION OF MEDICAL SPECIALISTS

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RECITALS

The UEMS and ESHG are active in areas relevant to the quality of medical specialist practice in rare and undiagnosed diseases in Europe primarily, but with global holistic availability and to the quality of care for the benefit of patients around the world. The Parties are willing to create a partnership that will promote and facilitate their activities in this area.

The overall goal of collaboration and cooperation is to define joint actions, to achieve the best possible outcomes and to increase visibility of both parties.

The parties seek through this Memorandum of Understanding (“*MoU*”) to define their partnership, to explore and to develop new opportunities in accordance with their objectives and competence. Through this MoU, the Parties also aim to establish an efficient and transparent communication between them.

THE PARTIES DECLARE THAT

1. SCOPE

This MoU outlines the principles of collaboration between the UEMS and ESHG.

2. INTENTION OF THE PARTIES

The Parties acknowledge that this MoU does not, and is not meant to, constitute a legally binding agreement between them. Whenever an activity undertaken by both Parties would require a formal legal framework Parties will conclude a formal, legally binding agreement.

The non-binding relationship between the UEMS and ESHG governed by this MoU is that of independent contractors. Nothing contained in this document will be construed as constituting any other relationship between the Parties.

This MoU does not prevent or limit ESHG or UEMS to enter agreements with other parties. Both Parties declare that they will not enter agreements that would jeopardize or invalidate this MoU and, whenever reasonable doubt would arise as to whether a new agreement is likely to be in conflict with this MoU, the Parties will communicate and strive to resolve outstanding issues.

UNION EUROPÉENNE DES MÉDECINS SPÉCIALISTES EUROPEAN UNION OF MEDICAL SPECIALISTS

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3. INTERNAL POLICIES

Subject to the terms of this MoU, the implementation and pursuit of the goals, objectives, conditions and terms of this collaboration will be carried out in accordance with the internal policies and procedures of each Party.

4. SCOPE OF COMPETENCES AND ROLES

a. ESHG

ESHG is a recognized international non-for profit organization, with its own statutes. Together with the American Society of Human Genetics and the Human Genetics Society of Australasia they founded the International Federation of Human Genetic societies, which represents a growing number of national societies. It currently has around 3,000 members. The ESHG is in regular contact with different directorates of the EU commission and other scientific organizations. The society has a partnership with some major diagnostic biotech companies to keep abreast of all the complex issues related to human genetics.

The goals of ESHG include:

- The task and purpose of the association is to promote research in basic and applied human and medical genetics, the development and assurance of high standards in clinical practice and to facilitate contacts between all persons who share these aims.
- The association carries out its activities as a non-profit association due to its purpose and without the intention of making a profit. The association pursues exclusively and directly objectives in public interest.
- The association strives for the integration of scientific research and its implementation in the clinical field as well as for (postgraduate) education of specialists and the public in all areas of medical and human genetics.
- It is not limited in its area of activity and is active throughout Europe in particular.

The purpose of the association shall be achieved by the material and non-material means listed below:

Non-material means:

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- Organisation of scientific training events (e.g. scientific congresses, seminars, national and international conferences as well as technical courses & symposia) for local and foreign physicians, scientists, Genetic Nurses and Genetic Counsellors and other specialists,
- Founding & allocation of travel grants for scientists within the framework of training events, assessed by professionally qualified bodies,
- Founding & awarding of scientific prizes and project funding, assessed by professionally qualified bodies,
- Publication of a scientific journal ("European Journal of Human Genetics") as a medium of the association
- Scientific support and expertise for projects in this field
- Support of initiatives that can contribute to the achievement of the association's goals
- Conducting field studies
- Exchange and dissemination of knowledge in the field of human genetics
- Participation in non-profit and/or for-profit societies or companies, if this serves to promote the tasks and the purpose of the association

Material means:

- Membership and participation fees of individuals and corporations
- Income from the organization and execution of scientific events
- Income from the corporate exhibition accompanying the events and sponsorship
- Income from the publication of scientific publications in printed or electronic form
- Subsidies, donations, collections, bequests and other contributions from private or public bodies
- Income from the management of own assets (e.g. interest income, income from participations, etc.)
- any other resource or benefit that does not conflict with applicable laws.

b. UEMS

According to its articles of association, the UEMS objectives are to promote the harmonization of training standards for specialist physicians within the European Union and to promote free movement of specialist doctors within the European Union. The UEMS is independent from medical industry in order to assure unbiased position in areas of medical politics and in accreditation of CME.

UNION EUROPÉENNE DES MÉDECINS SPÉCIALISTES EUROPEAN UNION OF MEDICAL SPECIALISTS

Association internationale sans but lucratif – International non-profit organisation

The key activities of the UEMS include:

- Political lobbying (European Commission, Parliament, Support of NMAs)
- Standard setting for specialist training and practice
- Accreditation of continuing medical education (CME) and continuing professional development (CPD)
- Control of exam procedures

The UEMS members are delegated by 41 National Medical Associations. Specialist Sections, their Divisions and Boards, and Multidisciplinary Joint Committees are UEMS bodies, created to promote and defend the interests of medical specialists in their respective fields and to improve the quality of medical specialist training and practice at the European level.

5. MUTUAL RECOGNITION

Each Party acknowledges the competences of the other, according to its articles of association.

Each Party acknowledges that the other is an essential partner in the development and improvement of the quality of **medical specialist practice of diagnosis, treatment, education and aftercare of the rare and undiagnosed patients and specialists involved in their care**. Parties recognize that their continued collaboration should be a crucial and integral element to the future success of both organizations and their members.

6. AREAS OF COOPERATION BETWEEN THE UEMS AND THE ESHG

Parties undertake to collaborate in order to achieve the objectives of mutual interest. The areas of collaboration between the UEMS and ESHG can include, but shall not be limited to:

- Elaboration of European, and worldwide specialist training curriculum
- Partnering in launch of European Board of Rare and Undiagnosed Diseases (EBRUD)
- Organisation of specialist European examinations available for worldwide candidates, participation in the EU Board Exam in Essentials in Rare and Undiagnosed Diseases.
- Participation in the the Enlarged Exam Steering Committee (EESC) of the above EU Exam
- Organisation of visitation programs
- Development and promotion of high quality, unbiased CME/CPD

UNION EUROPÉENNE DES MÉDECINS SPÉCIALISTES EUROPEAN UNION OF MEDICAL SPECIALISTS

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- Setting European, and worldwide standards of specialist practice
- Explore accreditation of training programmes and other educational activities such as conferences or webinars focused on the development of expertise in rare diseases
- Provision of joint opinion and statements to the EU/worldwide institutions
- Advocacy action including provision of joint opinion and statements to the EU institutions
- Networking between specialties. Engagement with both trainee representatives, medical experts, researchers and patient organizations and promote meaningful patient-professional-partnership.
- Delegating representative to the EBRUD Bureau

The UEMS and ESHG commit to working in close cooperation and to actively exchange information that is of common interest and/or might be of significance to both organizations and their members.

Parties recognize that:

- Each Party is a key partner in areas of collaboration described in this document
- ESHG concentrates on organization and networks of patients, researchers and experts, to engage in scientific research, development of practice guidelines and standards
- UEMS expertise concentrates on accreditation of CME/CPD, elaboration of Training Requirements and curricula and organization of European Examinations

Parties agree to involve the other Party when elaborating major policy documents at the earliest possible stage of the process in order to receive its input.

7. EUROPEAN BOARD

The UEMS and ESHG acknowledge that the MJC RUD is the framework for cooperation and the forum for discussion between representatives of both Parties. ESHG recognizes that MJC RUD is a UEMS body and should follow the rules of the UEMS described in its Statutes and Rules of Procedures.

The Parties will closely cooperate to establish satisfactory representation of each Party in MJC RUD.

The UEMS Boards are education arms of the UEMS entities. The parties aware that the UEMS, and UEMS MJC RUD goals include establishment and launch of the EBRUD. The ESHG hereby join to this endeavor, according to the spirit and basic principles of the present MoU.

UNION EUROPÉENNE DES MÉDECINS SPÉCIALISTES EUROPEAN UNION OF MEDICAL SPECIALISTS

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8. COMMUNICATION

The MJC RUD and the EBRUD, when it will be launched, will be in charge of communication with ESHG in all matters regarding areas of cooperation defined in this MoU, including communications to the UEMS Executive, other UEMS bodies and to UEMS constituency. This MoU does not change the UEMS representation rules described in statutory documents or waive information and approval duties of MJC RUD.

ESHG will communicate with MJC RUD and EBRUD in all matters regarding areas of cooperation defined in this MoU.

ESHG and the MJC RUD will each appoint a person for all contacts with the other party. Should there be a change in each Party's contact person, the partner shall inform each other as soon as possible.

Both parties will provide a link on their website to the other's website.

a. Official announcement

An official announcement of the present agreement will be made on both Parties websites as a common statement by the UEMS and ESHG after signature of the agreement. The statement will be also circulated to both Parties constituency.

9. REPRESENTATION

The President of ESHG or an appointed representative of ESHG is invited to take part to the UEMS MJC RUD's executive meetings.

Likewise, the President of the UEMS Section and Secretary or another representative of the MJC RUD is invited to take part in meetings of ESHG conferences, workshops or agreed meetings.

10. FUNDING

This MoU does not include the exchange of funds between parties.

11. MODIFICATION

This MoU can be modified or amended only by a writing signed by both parties.

UNION EUROPÉENNE DES MÉDECINS SPÉCIALISTES
EUROPEAN UNION OF MEDICAL SPECIALISTS

Association internationale sans but lucratif – International non-profit organisation

12. TERM AND TERMINATION

This MoU is concluded for an indefinite period.

13. EFFECTIVITY

This MoU is effective immediately upon signature of all parties here to.

Date: xxrd July, 2023



Vassilios Papalois
UEMS President

Borut Peterlin
ESHG President



João Grenho
UEMS Secretary General

XY
Position at ESHG

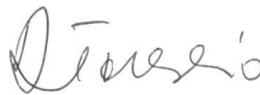


Béla Melegh
President of MJC RUD

Jerome del Piccia
Position at ESHG



Alessandra Renieri
Secretary of MJC RUD



Domenica Taruscio
Vice-President of MJC RUD



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F +32 2 640 37 30

coordination@uems.eu; ceo@uems.eu

MEMORANDUM OF UNDERSTANDING

BETWEEN:

(1) **UEMS (European Union of Medical Specialists)**; an international non-for-profit organization incorporated under the laws of Belgium, having its registered seat at 24 rue de l'Industrie, 1040 Brussels – Belgium, acting through its Multidisciplinary Joint Committee of Rare and Undiagnosed Diseases [MJC RUD], hereby validly represented by Vassilios Papalois, UEMS President, Joao Grenho, UEMS Secretary General, and Béla Melegh MJC RUD President, Alessandra Renieri, MJC RUD Secretary, Domenica Taruscio, MJC RUD Vice-President,

Hereafter: "UEMS"

and

(2) **EURO-NMD** is a European Reference Network for the thematic grouping of rare neuromuscular diseases (NMDs), a broad group of related disorders that represent a major cause of mortality and lifelong disability in children and adults. EURO-NMD unites 84 of Europe's leading NMD clinical and research centres in 25 Member States and includes highly active patient organizations. More than 150,000 NMD patients are seen annually by the ERN. The EURO-NMD coordination team are based in Pitié Salpêtrière Hospital in Paris, France. The team is led by EURO-NMD coordinator Tesresinha Evangelista.

Hereafter: "EURO-NMD"

The parties sub (1) and (2) shall hereafter be referred to individually as a "Party" and collectively as the "Parties".

PRESIDENT: VASSILIOS PAPALOIS
TREASURER: OTHMAR HAAS

SECRETARY-GENERAL: JOAO GRENHO
LIAISON OFFICER: ROMUALD KRAJEWSKI

UNION EUROPÉENNE DES MÉDECINS SPÉCIALISTES EUROPEAN UNION OF MEDICAL SPECIALISTS

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RECITALS

The UEMS and EURO-NMD are active in areas relevant to the quality of medical specialist practice in rare and undiagnosed diseases in Europe primarily, but with global holistic availability and to the quality of care for the benefit of patients around the world. The Parties are willing to create a partnership that will promote and facilitate their activities in this area.

The overall goal of collaboration and cooperation is to define joint actions, to achieve the best possible outcomes and to increase visibility of both parties.

The parties seek through this Memorandum of Understanding (“MoU”) to define their partnership, to explore and to develop new opportunities in accordance with their objectives and competence. Through this MoU, the Parties also aim to establish an efficient and transparent communication between them.

THE PARTIES DECLARE THAT

1. SCOPE

This MoU outlines the principles of collaboration between the UEMS and EURO-NMD.

2. INTENTION OF THE PARTIES

The Parties acknowledge that this MoU does not, and is not meant to, constitute a legally binding agreement between them. Whenever an activity undertaken by both Parties would require a formal legal framework Parties will conclude a formal, legally binding agreement.

The non-binding relationship between the UEMS and EURO-NMD governed by this MoU is that of independent contractors. Nothing contained in this document will be construed as constituting any other relationship between the Parties.

This MoU does not prevent or limit EURO-NMD or UEMS to enter agreements with other parties. Both Parties declare that they will not enter agreements that would jeopardize or invalidate this MoU and, whenever reasonable doubt would arise as to whether a new agreement is likely to be in conflict with this MoU, the Parties will communicate and strive to resolve outstanding issues.

UNION EUROPÉENNE DES MÉDECINS SPÉCIALISTES EUROPEAN UNION OF MEDICAL SPECIALISTS

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3. INTERNAL POLICIES

Subject to the terms of this MoU, the implementation and pursuit of the goals, objectives, conditions and terms of this collaboration will be carried out in accordance with the internal policies and procedures of each Party.

4. SCOPE OF COMPETENCES AND ROLES

a. EURO-NMD

EURO-NMD is a European Reference Network for the thematic grouping of rare neuromuscular diseases (NMDs), a broad group of related disorders that represent a major cause of mortality and lifelong disability in children and adults. NMDs are caused by acquired or genetic defects of motorneurons, peripheral nerves, neuromuscular junctions or skeletal muscle, resulting in muscle weakness and wasting, swallowing and breathing difficulties, and cardiac failure.

NMDs collectively affect an estimated 500,000 EU citizens and result in significant costs for families and the healthcare system. EURO-NMD unites 84 of Europe's leading NMD clinical and research centres in 25 Member States and includes highly active patient organizations. More than 150,000 NMD patients are seen annually by the ERN.

The goals of EURO-NMD include:

- harmonizing and implementing standards for clinical and diagnostic best practice,
- improving equity of care provision across Member States,
- decreasing time to diagnosis,
- increasing cost efficiency through better care pathways,
- access to specialist training and education,
- application of eHealth services,
- development and application of care guidelines,
- facilitating translational and clinical research,
- harmonizing data and samples for research reuse,
- sharing of high-quality data.

b. UEMS

UNION EUROPÉENNE DES MÉDECINS SPÉCIALISTES EUROPEAN UNION OF MEDICAL SPECIALISTS

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According to its articles of association, the UEMS objectives are to promote the harmonization of training standards for specialist physicians within the European Union and to promote free movement of specialist doctors within the European Union. The UEMS is independent from medical industry in order to assure unbiased position in areas of medical politics and in accreditation of CME.

The key activities of the UEMS include:

- Political lobbying (European Commission, Parliament, Support of NMAs)
- Standard setting for specialist training and practice
- Accreditation of continuing medical education (CME) and continuing professional development (CPD)
- Control of exam procedures

The UEMS members are delegated by 41 National Medical Associations. Specialist Sections, their Divisions and Boards, and Multidisciplinary Joint Committees are UEMS bodies, created to promote and defend the interests of medical specialists in their respective fields and to improve the quality of medical specialist training and practice at the European level.

5. MUTUAL RECOGNITION

Each Party acknowledges the competences of the other, according to its articles of association.

Each Party acknowledges that the other is an essential partner in the development and improvement of the quality of **medical specialist practice of diagnosis, treatment, education and aftercare of the rare and undiagnosed patients and specialists involved in their care**. Parties recognize that their continued collaboration should be a crucial and integral element to the future success of both organizations and their members.

6. AREAS OF COOPERATION BETWEEN THE UEMS AND THE EURO-NMD

Parties undertake to collaborate in order to achieve the objectives of mutual interest. The areas of collaboration between the UEMS and EURO-NMD can include, but shall not be limited to:

- Elaboration of European, and worldwide specialist training curriculum
- Partnering in launch of European Board of Rare and Undiagnosed Diseases (EBRUD)
- Organisation of specialist European examinations available for worldwide candidates
- Organisation of visitation programs

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- Development and promotion of high quality, unbiased CME/CPD
- Setting European, and worldwide standards of specialist practice
- Explore accreditation of training programmes and other educational activities such as conferences or webinars focused on the development of expertise in rare diseases
- Provision of joint opinion and statements to the EU/worldwide institutions
- Advocacy action including provision of joint opinion and statements to the EU institutions
- Networking between specialties. Engagement with both trainee representatives, medical experts, researchers and patient organizations and promote meaningful patient-professional-partnership.

The UEMS and EURO-NMD commit to working in close cooperation and to actively exchange information that is of common interest and/or might be of significance to both organizations and their members.

Parties recognize that:

- Each Party is a key partner in areas of collaboration described in this document
- EURO-NMD concentrates on organization and networks of patients, researchers and experts, to engage in scientific research, development of practice guidelines and standards
- UEMS expertise concentrates on accreditation of CME/CPD, elaboration of Training Requirements and curricula and organization of European Examinations

Parties agree to involve the other Party when elaborating major policy documents at the earliest possible stage of the process in order to receive its input.

7. EUROPEAN BOARD

The UEMS and EURO-NMD acknowledge that the MJC RUD is the framework for cooperation and the forum for discussion between representatives of both Parties. EURO-NMD recognizes that MJC RUD is a UEMS body and should follow the rules of the UEMS described in its Statutes and Rules of Procedures.

The Parties will closely cooperate to establish satisfactory representation of each Party in MJC RUD.

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The UEMS Boards are education arms of the UEMS entities. The parties aware that the UEMS, and UEMS MJC RUD goals include establishment and launch of the EBRUD. The EURO-NMD hereby join to this endeavor, according to the spirit and basic principles of the present MoU.

8. COMMUNICATION

The MJC RUD and the EBRUD, when it will be launched, will be in charge of communication with EURO-NMD in all matters regarding areas of cooperation defined in this MoU, including communications to the UEMS Executive, other UEMS bodies and to UEMS constituency. This MoU does not change the UEMS representation rules described in statutory documents or waive information and approval duties of MJC RUD.

EURO-NMD will communicate with MJC RUD in all matters regarding areas of cooperation defined in this MoU.

EURO-NMD and the MJC RUD will each appoint a person for all contacts with the other party. Should there be a change in each Party's contact person, the partner shall inform each other as soon as possible.

Both parties will provide a link on their website to the other's website.

a. Official announcement

An official announcement of the present agreement will be made on both Parties websites as a common statement by the UEMS and EURO-NMD after signature of the agreement. The statement will be also circulated to both Parties constituency.

9. REPRESENTATION

The President of EURO-NMD or an appointed representative of EURO-NMD is invited to take part to the UEMS MJC RUD's executive meetings.

Likewise, the President of the UEMS Section and Secretary or another representative of the MJC RUD is invited to take part in meetings of EURO-NMD conferences, workshops or agreed meetings.

10. FUNDING

This MoU does not include the exchange of funds between parties.

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11. MODIFICATION

This MoU can be modified or amended only by a writing signed by both parties.

12. TERM AND TERMINATION

This MoU is concluded for an indefinite period.

13. EFFECTIVITY

This MoU is effective immediately upon signature of all parties here to.

Date: 3rd March 2022



Vassilios Papalois
UEMS President

Tereshina Evangelista
EURO-NMD Coordinator



João Grenho
UEMS Secretary General

Marianne de Visser
Position at EURO-NMD

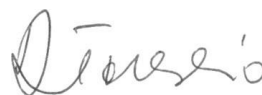


Béla Melegh
President of MJC RUD

XY
Position at EURO-NMD



Alessandra Renieri



Domenica Taruscio

UNION EUROPÉENNE DES MÉDECINS SPÉCIALISTES
EUROPEAN UNION OF MEDICAL SPECIALISTS

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Secretary of MJC RUD

Vice-President of MJC RUD

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coordination@uems.eu; ceo@uems.eu

Enlarged Exam Steering Committee (EESC) of MJC RUD/EBRUD

1., The EESC was established based on the decision of the 2022 MJC RUD Annual Membership meeting, to create a body with the complete and exclusive authorization of the coordination and management of all exam tasks, with a once renewable 4 year-long mandate (starting from January 2023) for each EESC members.

2., The EESC has UEMS and non UEMS members. The UEMS members are delegated by the UEMS Bodies, after an internal call circulated via the MJC RUD members, with the supervision of the UEMS Exec and UEMS Coordination in the electronic delegation procedure, as witnessing and approving authorities. The invited/delegated UEMS nominees were confirmed by election by electronic vote of MJC RUD members.

3., The EESC is governed by the Bureau (Chair, vice Chairs, Secretary, and Liaison officer) under the principles defined by the UEMS RoP for these positions. The Bureau has the exclusive authorization for the coordination of the invitation, election, and replacement of the non-UEMS members.

4, The following colleagues were delegated/invited into the EESC:

UEMS Bodies (EESC Governing Bureau in bold):

Serdar Ceylaner	chair
Artur Beke	vice chair
Josanne Vassallo	vice chair
Jean Calleja Agius	secretary
Béla Melegh	liaison officer

Domenica Taruscio

Alessandra Renieri

Aidan Ryan

Nursel Calik Basaran

External EU Partners:

Wendy van Zelst-Stams	clinical genomic medicine advisor
Birute Tumiene	EU networking advisor
Joel Ferri	WGRDBTH
Gülay Ceylaner	laboratory genetics
Simone Baldovio	
Wouter te Rijdt	junior doctors (genetics)

External international partners

William Gahl	UDNI liaison
Bruce Korf	scientific advisor
Gareth Baynam	global network advisor
Eva Morava	metabolic diseases
Olaf Bodamer	training courses coordinator
Cyndi Tifft	clinical training advisor
Elizabeth Palmer	UDNI DG
Paul Lasko	international affairs advisor
David Adams	data sharing advisor
Saumya Shekhar Jamuar	precision medicine
Ratna Puri	
Sian Gannon	clinical education advisor

Patient advocacy Groups

Matt Boltz Johnson	EURORDIS
Helene Cederroth	Wilhelm Foundation



**MULTIDISCIPLINARY JOINT COMMITTEE OF RARE AND
UNDIAGNOSED DISEASES (MJC RUD)**

AND

**EUROPEAN BOARD OF RARE AND UNDIAGNOSED DISEASES
UNION EUROPÉENNE DES MÉDECINS SPÉCIALISTES (UEMS)**

Working under the title of

The Council for European Specialist Medical Assessment (CESMA-UEMS)

Declaration of Confidentiality

European Certificate Regarding

Essentials of Rare and Undiagnosed Diseases

With respect to the Enlarged Examination Steering Committee (EESC) of the European Certificate in Essentials of Rare and Undiagnosed Diseases, I agree to maintain the highest standards of confidentiality in relation to all examination inquiries of which the Committee freely and dutifully extends to me.

I agree not to divulge the content of the examination inquiry material to individuals beyond the scope of the EESC, and I agree to retain such materials in a place of safety while it is in my possession. I shall undertake all reasonable measures to ensure inquiry materials are securely transmitted in full accordance to the protocols of the EESC.

If and when deemed appropriate, in full compliance to the statutes of the EESC, I agree to destroy such examination inquiry material in its entirety, ensuring all relevant content will not be divulged nor distributed.

Name:

Position:

Institution:

Address:

.....
.....
.....

Signed:

Date: