



**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

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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.

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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

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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

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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 Coordinator 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: 1st December 2023



Vassilios Papalois
UEMS President



Holm Graessner
ERN-RND Coordinator



Jean Grenho
UEMS Secretary General



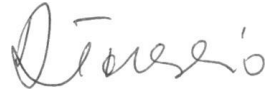
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Béla Melegh
President of MJC RUD



Alessandra Renieri
Secretary of MJC RUD



Domenica Taruscio
Vice-President of MJC RUD