



UNION EUROPÉENNE DES MÉDECINS SPÉCIALISTES EUROPEAN UNION OF MEDICAL SPECIALISTS

Association internationale sans but lucratif

International non-profit organisation

RUE DE L'INDUSTRIE, 24
BE- 1040 BRUSSELS
www.uems.eu

T +32 2 649 51 64
info@uems.eu

UEMS 2020 / 15

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 Paplois, UEMS President; Joao Grenho, UEMS Secretary General, and Béla Melegh MJC RUD President,

Hereafter: "UEMS"

and

2. Undiagnosed Disease Network International (UDNI), a Medical and Scientific network, hereby represented by Eric Klee, head of UDNI Membership Committee (permanent position: Director of Bioinformatics, Center for Individualized Medicine, Mayo Clinic, MN, USA), Domenica Taruscio UDNI Governing Board (permanent position: Director of the National Centre for Rare Diseases, Istituto Superiore di Sanità, Rome, Italy) and Gareth Baynam, UDNI Governing Board (permanent position: Western Australian Health Department).

Hereafter: "UDNI"

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



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RECITALS

The UEMS and UDNI 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 cooperation and collaboration between the UEMS and UDNI.

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 the UDNI 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 UDNI 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) UDNI

According to its articles of association, the UDNI mission is to

UDNI Principles	UDNI Implementation Approaches
1) Engage centers with experience in undiagnosed and rare diseases	Open membership to clinical and non-clinical members from around the world who are conducting undiagnosed diseases research.
2) Foster a collaborative research community	Hold periodic face-to-face meetings in international venues.
3) Establish a cooperative governance structure	Develop a process for membership involvement in key UDNI-wide decisions.
4) Design common research procedures	Clinical and basic research: to be determined annually.
5) Provide a high-quality patient evaluation	Establish UDNI-wide clinical and phenotypic evaluation methods and guidelines for patient acceptance.
6) Provide a high-quality patient experience	Establish feedback from patients
7) Collect data in accordance with recognized data standards	Annotate clinical data with Human Phenotype Ontology. Follow international standards for human genomic data sharing.
8) Protect patient data	Develop and use accepted informed consent procedures, according to international standards for protecting research participants.
9) Expect broad data sharing	Share data both within and outside of the UDNI.
10) Stimulate dissemination of research results	Publish research results. Develop policies for UDNI-wide publications.
11) Ensure a high-functioning network	Establish formal procedures for monitoring the progress of the UDNI.

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



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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.

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 INTERNATIONAL SOCIETY

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

- Elaboration of European, and worldwide specialist training curriculum
- 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
- Provision of joint opinion and statements to the EU/worldwide institutions

The UEMS and the UDNI 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;
- UDNI focuses on organization of network described under 4A, organization of CME/CPD, scientific research, development of practice guidelines and standards;
- UEMS expertise concentrates on accreditation of CME/CPD, elaboration Training Requirements and curricula and organization of European Examinations.

Parties agree to involve the other Party when elaborating major policy documents at the



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earliest possible stage of the process in order to receive its input.

7. COMMUNICATION

The MJC RUD will be responsible for communication with the UDNI 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 the statutory documents or waive information and approval duties of MJC RUD.

The UDNI will communicate with the UEMS in all matters regarding areas of cooperation defined in the MoU.

The UDNI 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 the UDNI after signature of the agreement. The statement will be also circulated to both Parties constituency.

8. REPRESENTATION

The President of the UDNI or an appointed representative of the UDNI is invited to take part to the 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 the meetings of UDNI governing Board Meetings.

9. FUNDING

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



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10. MODIFICATION

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

11. TERM AND TERMINATION

This MoU is concluded for an indefinite period.

12. EFFECTIVITY

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

Date:

Vasilios Papalois
UEMS President

Eric Klee
Head of UDNI Membership Committee

Joao Grenho
UEMS Secretary General

Domenica Taruscio
UDNI Governing Board

Gareth Baynam
UDNI Governing Board

Bela Meleg
UEMS MJC RUD President