

European Certificate
in
Essentials in Rare and Undiagnosed Diseases (EC RUD)
UEMS[†] Multidisciplinary Joint Committee on Rare and Undiagnosed
Diseases (UEMS-MJC RUD)
with
UEMS European Board of Rare and Undiagnosed Diseases (EBRUD)

in collaboration with

Undiagnosed Disease Network International UDNI
EURORDIS, The Rare Care Centre, Perth Children's Hospital
& the Wilhelm Foundation

Description of the
EC RUD Assessment and Examination system

[†] *Union Européenne des Médecins Spécialistes (European Union of Medical Specialists)*

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1. MOTIVATION – WHY YOU SHOULD TAKE THE EC RUD EXAM

1.1 The European Board Examination in Essentials of Rare and Undiagnosed Diseases aims to establish a standardized benchmark of excellence for healthcare professionals across Europe and beyond. This initiative aligns with the principles set forth by the Union Européenne des Médecins Spécialistes (UEMS) and its Council for European Specialists Medical Assessment (CESMA), emphasizing the importance of harmonized assessments to ensure consistent and high-quality care for patients with rare and undiagnosed conditions.

1.2 Advantages of the Examination include:

1.2.1 **Standardization of Knowledge and Skills:** The examination provides a unified framework to assess and validate the competencies of medical professionals in the field of rare and undiagnosed diseases, ensuring consistent standards across Europe and beyond.

1.2.2 **Enhanced Professional Mobility:** Achieving certification facilitates the free movement of specialists among EU member countries and beyond, promoting cross-border collaboration and knowledge exchange.

1.2.3 **Recognition of Excellence:** The certification serves as a mark of distinction, acknowledging the holder's expertise and commitment to the highest standards of patient care in this specialized field. It is not a working license, but definitely is an advantage in the holder's employment.

1.2.4 **Complementary to National Qualifications:** While reinforcing national certifications, this European examination offers an additional layer of validation, harmonizing competencies across different healthcare systems that is not limited to Europe.

1.2.5 **Promotion of Continuous Professional Development:** The examination encourages ongoing learning and adaptation to emerging challenges and advancements in the diagnosis and management of rare diseases.

1.2.6 **Alignment with European Reference Networks (ERNs):** By standardizing specialist knowledge, the examination supports the objectives of ERNs in facilitating cross-border research, diagnosis, and treatment of rare diseases.

1.2.7 **Membership to European Board (degree of "Fellow of EBRUD" received) automatically is a membership in community with the advantage of participation of the activities on the EBRUD and it's strategic partners (UDNI, EURORDIS, etc).**

2. PREAMBLE

- 2.1. The assessment and certification process under the European Diploma for Essentials in Rare and Undiagnosed Diseases (EC RUD) is a joint initiative developed by the UEMS Multidisciplinary Joint Committee of Rare and Undiagnosed Diseases (MJC RUD) in collaboration with its partner organizations.
- 2.2 With thousands of rare diseases (RD) identified, we support a care model in which patients are treated through complex, multidisciplinary, and cross-sectoral approaches. These are delivered by specialized organizations that bring together a wide range of expert competencies.
- 2.3 The MJC RUD was established to coordinate rare disease-related activities within UEMS and to represent UEMS in collaborations with external stakeholders in the field of rare diseases. While recognizing the independent contributions of other UEMS sections and boards—many of which have made significant advances in specific rare disease topics—the MJC RUD also acknowledges that care for some rare diseases or disease groups may be primarily coordinated by a single specialty or by a combination of specialties.
- 2.4 There is a growing demand—from patients and advocacy groups, policymakers, and the medical and scientific communities—for a comprehensive training and assessment framework focused on the core aspects of rare and undiagnosed diseases. This includes the creation of a standardized program to train and certify experts equipped to serve the rare disease community.
- 2.5 EC RUD serves as a recognized, skill- and knowledge-based assessment for medical doctors who are involved in the care of patients with rare diseases—particularly in complex clinical scenarios where diagnosis and management present unique challenges. The required competencies range from the initial recognition of "red flag" patients who may warrant further investigation, to coordinating diagnostics and organizing comprehensive care pathways. Key elements are outlined in the European Training Requirements (ETR) for Rare and Undiagnosed Diseases, approved by the UEMS Council in 2019.
- 2.6 Certification is awarded to selected medical doctors as outlined in the ETR. The goals are to establish world-class competence standards and to build a certified expert community. Those who pass the examination will earn the title Fellow of the European Board of Rare Diseases.
- 2.7 The examination is administered and overseen by the Enlarged Examination Steering Committee (EEST) and its subgroups, with observers from partner organizations. Representatives from UEMS committees may also attend as appropriate.
- 2.8 The EC RUD certification is valid for life and is regarded as a mark of excellence. Recipients are entitled to use the title Fellow of EC RUD. However, it will be considered a license to practice only in countries that formally recognize and ratify it for that purpose.
- 2.9 MJC RUD/EC RUD also supports the ongoing development of professional standards through Continuing Medical Education and Continuing Professional Development (CME/CPD). Participation in this process is strongly recommended for practicing professionals every 4–5 years.
- 2.10 The European examination system is open globally, and candidates of any nationality are welcome to apply.

3. ADVANTAGES OF HOLDING EUROPEAN EXAM¹

- 3.1 The UEMS is committed to establishing strong foundations for advanced medical training across Europe, with the goal of elevating healthcare standards to a world-class level in a fair and consistent way across its member states. This initiative aims to ensure that the highest quality of healthcare delivery is achieved not only in Europe, but eventually on a global scale.
- 3.2 EC RUD represents a major advancement in setting standardized competencies for rare and undiagnosed diseases across Europe—and, in time, for all countries that choose to join this initiative. The ultimate objective is to improve and harmonize the delivery of services that are currently highly variable and fragmented across different nations.
- 3.3 Fellows of the European Board of Rare and Undiagnosed Diseases will form part of a professional community, providing a platform for continued education—for themselves and for others. This network is also expected to support international mobility for experts working in the rare disease field and to foster their recognition as a distinct and specialized professional community.
- 3.4 Passing the EC RUD examination demonstrates that a candidate possesses the necessary knowledge base to practice as an expert in rare and undiagnosed diseases. Successfully completing the exam—along with a maintained record of Continuing Medical Education and Professional Development (CME/CPD)—reflects a commitment to lifelong learning. However, essential qualities such as clinical skills, practical competencies, and professional behavior must be assessed continuously through supervised clinical experience and evaluations, along with demonstrated ability to work effectively within teams.
- 3.5 UEMS and EC RUD partners will actively seek national recognition of the EC RUD certification, as has already been accomplished for other medical specialties. The goal is for this certification to become a meaningful component of a Fellow's professional qualifications, supporting their practice and employability across various healthcare systems.

4. ELIGIBILITY CRITERIA

- 4.1 Examinations within the UEMS system are primarily designed for medical trainees in the final stages of their specialist training—typically the year prior to qualification as fully certified clinical practitioners under national board systems. However, any medical doctor holding a valid medical qualification may apply to sit the EC RUD examination, provided they meet the following criteria: their training aligns with at least 80% of the terms outlined in the most recent approved version of the European Training Requirement (ETR), their documentation is approved by the Enlarged Examination Steering Committee (EESC), and the admission fee has been paid. Eligible candidates must hold a medical degree (MD, or in some countries, MB ChB/BS).
- 4.2 Applicants must provide proof of eligibility by submitting a notarized copy of their medical qualification along with sufficient documentation verifying their active involvement in the care of patients with rare diseases.
- 4.3 Any candidate found to be soliciting confidential information from EEST members regarding any aspect of the examination will be disqualified from taking the exam and may forfeit any

¹ In accordance to the "Glasgow Declaration" by the UEMS (appended at the end)

admission fee already paid. Furthermore, if it is discovered that a candidate obtained the EC RUD certificate through dishonest or unethical means, the certificate will be revoked.

5. APPLICATION PROCEDURE

- 5.1 By applying to sit the EC RUD examination, candidates confirm their agreement to undertake the exam in the established format and structure. They also acknowledge that any cancellations must comply with the official cancellation policy.
- 5.2 Registration for the exam takes place on the following link: <https://mjcrud-uems.ptc.hu/content/Registration>
- 5.3 For inquiries please email: uboardexamrare@gmail.com
- 5.4 Applicants must provide accurate personal information, including their full name, as this data will be used on official certificates. The application must also include the required examination fee (in Euros) and valid contact details for receiving examination results. The official application date will be considered the date on which the funds are transferred to the UEMS MJC RUD bank account. Proof of transfer must be emailed to: uboardexamrare@gmail.com

- 5.4 The Bank details are as follows:

Account name:	UEMS /S. Union Europeenne Des Medecins Specialistes Aisbl
IBAN code:	BE72 0019 8888 9616 EUR
BIC code:	GEBABEBB
Bank address:	BNP Paribas Fortis SA/NV Montagne du Parc/Warandeborg 3 B-1000 Brussels

- 5.5 In order to comply with Belgian Law, the following procedure regarding the title of transfer must be followed:
- Please include the title of transfer:
"EXAM – THE NAME OF EXAMINEE / CANDIDATE - COUNTRY"
 - Please do not refer to 'payment' or 'invoice'
 - Payments should be made free of bank charges; therefore, applicants are required to cover costs associated with the bank transfer.

6. EXAMINATION ADMISSION FEES AND CATEGORIES (in EUROS):

- 6.1 The admission fee for the EC RUD examination is listed below and applies to the year 2026. Fees will be reviewed annually. Additional charges may apply in cases where administrative irregularities require further processing.
- 6.2 Cancellations made more than 28 days before the examination date will allow the application to remain valid for the following year's exam (2027). Cancellations made less than 28 days prior to the exam are non-refundable.
- 6.3 The examination fee is 150 EUR.

7. EXAMINATION STRUCTURE AND CONTENT

7.1 The EC RUD examination is primarily a knowledge-based assessment, aligned with the established curriculum (European Training Requirements, or ETR) and the official syllabus, available at: <https://mjcrud-uems.pt.ehu/content/etrs>. In addition to knowledge, the exam also aims to partially assess clinical skills (competencies) and professional attitudes, particularly in the areas of clinical reasoning, problem-solving, and medical ethics. This approach reflects the core professional roles promoted by UEMS: Medical Expert, Communicator, Scholar, Health Advocate, and Professional.

7.2 To qualify successfully, candidates must complete both parts of the examination.

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The scores from both sections will be combined and converted into a final percentage score.

8. TRIAL EXAM STRUCTURE AND CONTENT

8.1 The EC RUD examination will consist solely of Multiple Choice Questions (MCQs). However, the Enlarged Examination Steering Committee (EESC) reserves the right to revise the exam format in the future and introduce additional types of assessment methods.

8.2 The exam will have the following structure with 100 MCQs in total:

10 MCQs in RD general, and guidelines / newborn screening incl.

10 MCQs in basic genomics relevant for RD

10 MCQs in laboratory genomics

5 MCQs in general clinical laboratory problems

5 MCQs in treatment options

5 MCQs in diagnostic networks

5 MCQs in legislation issues

10 MCQs examples in neurogenetics

10 MCQs examples in metabolic diseases

10 MCQs in pediatric rare diseases

5 MCQs on phenotyping, coding, ontologies, digital health and devices

5 MCQs In public health issues including: advocacy; ethics, legal and social implications; policy and legislation

5 MCQs in ophthalmology, dermatology, immunology

5 .MCQs in patient advocacy and patient navigation

9. EXAMINATION VENUE AND SCHEDULE

9.1 The trial examination will be conducted entirely in an electronic format. In the future, the examination is expected to take place in secure, dedicated facilities without public access. Additionally, the Enlarged Examination Steering Committee (EESC) is expected to develop a model for conducting examinations in conjunction with relevant professional conferences or events.

10. EXAMINATION OUTCOME

10.1 By registering for the examination, candidates acknowledge and accept that the examination results are final. No legal appeal or dispute regarding the outcome will be permitted.

10.2 The pass mark will be determined using the Angoff method—a recognized rank-ordering evaluation technique—as a primary reference, along with other statistical methods as appropriate. These evaluations will be conducted by a professional statistician with expertise in examination methodology and data analysis.

10.3 Independent, external assessors will be appointed to ensure the fairness and integrity of the final marking process.

10.4 To achieve an overall pass, candidates must obtain a ‘Pass’ in both sections of the examination.

10.5 Unsuccessful candidates will receive limited feedback; however, appeals against the final decision will not be accepted.

11. ENLARGED EXAMINATION STEERING COMMITTEE (EESC)

11.1 The activities of the Enlarged Examination Steering Committee (EESC) are conducted under the exclusive authority of the EESC Bureau.

11.2 The EESC is responsible for the full examination process, including:

- Designing the exam structure
- Writing and selecting questions
- Establishing standard-setting and quality control procedures
- Appointing examiners and independent assessors
- Organizing and overseeing the examination administration

11.3 The EESC consists of approximately 20 to 30 members, delegated by the UEMS and invited from relevant scientific societies. External members are selected based on their recognized expertise in the field of rare diseases.

11.4 The Question Writing Group (QWG) is responsible for developing Multiple Choice Questions (MCQs) and maintaining the official MCQ question bank.

11.5 All EESC members are required to maintain strict confidentiality and must sign confidentiality agreements covering all aspects of the examination, including question materials. Any member found to have breached confidentiality will have their membership immediately terminated.

12. INDEPENDENT ASSESSORS

12.1 Official assessors will be appointed by the UEMS European Accreditation Council for Continuing Medical Education (EACCME), under whose authority the entire examination system will operate.

12.2 All assessors must formally commit to maintaining confidentiality regarding all examination materials and processes.

12.3 It is anticipated that representatives from patient advocacy groups—who have collaborated in the development and ongoing support of the examination to promote quality in rare disease services across Europe—will participate as independent assessors.

12.4 Additional observer-assessors will be appointed by the EESC Bureau.

13. EXAMINERS

13.1 A panel of independent examiners is recruited and appointed by the EESC Bureau.

13.2 The minimum criteria for appointment as an external examiner are as follows:

- i. The examiner's national specialist organization must be a member of the UEMS.
- ii. External experts must hold a recognized medical qualification and have a minimum of five years of clinical experience related to rare diseases.
- iii. Prior experience in examination processes is considered an advantage.

13.3 All examiners are required to sign a confidentiality agreement and pledge confidentiality regarding all examination materials and procedures.



GLASGOW DECLARATION

Representatives of the following UEMS Sections/Boards met in Glasgow on the 9th February 2007 and unanimously agreed the following:

1. The role of European Board Examinations is complementary to National Examinations where they exist.
2. Countries which do not have their own examination are encouraged to consider using the appropriate European Board Examinations.
3. European Board Examinations are regarded as a quality mark for safe independent practice at the end of specialist training.
4. All European Board Examinations shall publish both a syllabus and minimum requirements for examination.
5. Candidates for examination should be certified specialist or have been trained according to the relevant syllabus.
6. A trainee may sit the final part of a European Board Examinations provided they have fulfilled the requirements of their national training body where one exists or when approaching the end of the training.
7. Candidates of any nationality shall be eligible to sit the European Board Examinations.
8. Candidates who pass a European Board Examination and who are certified specialists in an EU/UEMS member state may call themselves "Fellow of the European Board". Other successful candidates will be "European Board Certified".
9. Trade sponsorship should not be used to subsidise the examination.
10. It is proposed to establish a Council for European Specialist Medical Examinations (CESME) as an advisory body to the UEMS and its sections.