



## RARE DISEASE RESEARCH TRAINING CERTIFICATE PROGRAM

An online "Rare Diseases Researcher Training Certificate Program" will be held by **Ege University Faculty of Medicine, Ege Rare Diseases Research Group, EGESEM** (Ege University Continuous Education Center) **and UZEM** (Ege University Distance Education Implementation and Research Center) with the organization of **EÜ EBİLTEM-TTO**.

The program will last 7 weeks as a training series on Thursdays from 20 May to 1 July 2021. It is obligatory to participate in 80% of the program. Participants will receive a certificate according to the certification exam to be held after the program.

[Click](#) to register for the certificate program to be carried out via Microsoft Teams application. The online meeting link will be sent to you before the certification program.

### PROGRAM

#### **First Week (May 20, 2021)**

#### **14:00 – 14:20 Opening Remarks (Welcome speech)**

**Prof. Şenay ŞANLIER**, *Director, EÜ EBİLTEM-TTO*

**Prof. Necdet BUDAK**, *Rector, Ege University (if his schedule allows he will participate)*

#### **14:20 – 14:50 Expectations and Pre-Assessment**

**Prof. Meral Kayıkçıoğlu**, *Department of Cardiology, Faculty of Medicine, Ege University*

#### **14:50 - 15:10 Overview of Rare Diseases and Basic Concepts**

**Prof. Ferda Özkınay**, *Department of Pediatrics, Faculty of Medicine, Ege University*

#### **15:10 -15:30 General Situation in Rare Diseases in Our Country; As an Example Metabolic Diseases**

**Prof. Mahmut Çoker**, *Department of Pediatrics, Faculty of Medicine, Ege University*

#### **15:30-15:45 What are The Unmet Needs in Rare Diseases?**

**Prof. E. Nihal Mete Gökmen**, *Department of Internal Medicine, Faculty of Medicine, Ege University*



**15:45-16:00**    **Legal and Regulatory Aspects of Rare Diseases, Challenges and Obstacles in Access to Medicine**

*Prof. Ayşe Nur Yüceyar, Department of Neurology, Faculty of Medicine, Ege University*

**16:00-17:00**    **End-of-Day Evaluation**

*Prof. Meral Kayıkçioğlu, Department of Cardiology, Faculty of Medicine, Ege University*

**Second Week (May 27, 2021)**

**14:00-14:30**    **Clinician-Researcher Crosstalk in The Genetic Diagnosis of Rare Diseases**

*Alberto Lopez Lera, Centre for Biomedical Network Research on Rare Diseases, Spain*

**14:30-14:50**    **Genetic Research in Rare Diseases**

*Prof. Muhsin Özgür Çoğulu, Department of Pediatrics, Faculty of Medicine, Ege University*

**14:50 – 15:10**    **Importance of Family Screening in Rare Diseases Research**

*Prof Hüseyin Onay, Multigen Genetic Diseases Evaluation Center*

**15:10 – 16:00**    **End-of-Day Evaluation**

*Assoc. Prof. Özge Altun Köroğlu, Department of Pediatrics, Faculty of Medicine, Ege University*

**Third Week (June 3, 2021)**

**14:00 – 15:30**    **Research Design and Methods**

*Assoc. Prof. Özge Altun Köroğlu, Department of Pediatrics, Faculty of Medicine, Ege University*

**14:30-15:00**    **Registry Based Research**

*Prof. Mustafa Kılıçkap, Department of Internal Medicine, Faculty of Medicine, Ankara University*

**15:00 – 15:30**    **How to Prepare Study Protocol for Rare Diseases' Research**

*Prof. Meral Kayıkçioğlu, Department of Cardiology, Faculty of Medicine, Ege University*



**15:30 – 16:00 End-of-Day Evaluation**

**Prof. Meral Kayıkçioğlu, Department of Cardiology, Faculty of Medicine, Ege University**

**Fourth Week (June 10, 2021)**

**14:00 - 14:30 Ethical Aspects in Rare Diseases Research**

**Prof. İsmail Hakkı Ayhan, Retired Lecturer (Department of Pharmacology), Founder of TR Ethics Committees**

**14:30 – 15:00 Clinical Trials in Rare Diseases and Adaptive Models**

**Prof. Hamdi Akan, Retired Lecturer (Department of Hematology, Ankara University Clinical Research Unit)**

**15:00 – 16:00 End-of-Day Evaluation**

**Assoc. Prof. Özge Altun Köroğlu, Department of Pediatrics, Faculty of Medicine, Ege University**

**Fifth Week (June 17, 2021)**

**14:00 - 14:30 Pediatric Clinical Trials in Rare Diseases, Gene Therapy etc.**

**Prof. Kaan Kavaklı, Department of Pediatrics, Faculty of Medicine, Ege University**

**14:30 – 15:00 Good Clinical Practice (GCP) in Rare Diseases Research; Researcher-Observer-Sponsor Responsibilities**

**Prof. Hasan Tekgül, Department of Child Neurology, Faculty of Medicine, Ege University**

**15:00- 15:20 Transparency and Open Access in Rare Disease Research**

**Nurşah Çetinkaya, Clinical Research Association**

**15:20- 15:50 Genome Editing Techniques in Rare Disease Research**

**Assoc. Prof. Tahir Atik, Department of Child Genetics, Faculty of Medicine, Ege University**

**15:50 – 16:00 End-of-Day Evaluation**

**Prof. Meral Kayıkçioğlu, Department of Cardiology, Faculty of Medicine, Ege University**



**Sixth Week (June 24, 2021)**

**14:00 - 14:30** Medical Writing: The Editor's Perspective

*Prof. Nikki Katsiki, Aristotle University of Thessaloniki*

**14:30 – 15:00** How to Publish an Article? (Journal Selection, Submission, Cover Letter, Revision)

*Prof. Marcus Maurer, Charité University Medicine*

**15:00 – 16:00** End-of-Day Evaluation

*Assoc. Prof. Özge Altun Köroğlu, Department of Pediatrics, Faculty of Medicine, Ege University*

**Seventh Week (July 1, 2021)**

**14:00 – 14:30** Research Networking for Rare Diseases.

*Prof. Fahri Şahin, Department of Internal Medicine, Faculty of Medicine, Ege University*

**14:30 – 15:00** Experiences of Receiving European Union Support

*Assoc. Prof. Emre Divarçı, Department of Pediatric Surgery, Faculty of Medicine, Ege University*

**15:00 – 15:30** The Role of Advocacy and Patient Associations in Rare Disease Research

*Gülin Dönmez, Molecular Biology and Genetics Specialist, OGDÄ Consultancy SL, Barcelona, Catalonia, Spain.*

**15:30 – 16:00** Artificial Intelligence in Rare Diseases Research

*Ege Doğan Dursun, Freelance Web Designer*

**16:00 – 17:00** Closing and Wrap-up Remarks



## CONTRIBUTORS

*Prof. Necdet BUDAK*

*Prof. Şenay ŞANLIER*

*Prof. Meral KAYIKÇIOĞLU*

*Prof. Ferda ÖZKINAY*

*Prof. Mahmut ÇOKER*

*Prof. E. Nihal METE GÖKMEN*

*Prof. Ayşe Nur YÜCEYAR*

*Prof. Muhsin Özgür ÇOĞULU*

*Prof. Mustafa KILIÇKAP*

*Prof. İsmail Hakkı AYHAN*

*Prof. Hamdi AKAN*

*Prof. Kaan KAVAKLI*

*Prof. Hasan TEKGÜL*

*Prof. Nikki KATSIKI*

*Prof. Marcus MAURER*

*Prof. Fahri ŞAHİN*

*Prof. Hüseyin ONAY*

*Assoc. Prof. Emre DİVARCI*

*Assoc. Prof. Tahir ATİK*

*Assoc. Prof. Özge ALTUN KÖROĞLU*

*Alberto Lopez LERA*

*Nurşah ÇETİNKAYA*

*Gülin DÖNMEZ*

*Ege Doğan DURSUN*

## Organizing Committee

*Prof. Meral KAYIKÇIOĞLU*

*Assoc. Prof. Özge ALTUN KÖROĞLU*