

SCIENTIFIC COORDINATOR:

Professor Dr. med. BENEDIKT SCHOSER, FEAN
Friedrich Baur Institute
Neurology Clinic and Outpatient Department
LMU University Hospital
Ludwig Maximilian University of Munich

SPEAKERS:**ATALAIA ANTONIO**

APHP Pitié Salpêtrière, Inserm U974, Myology Research Center,
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Head of the Translational Myotonic Dystrophy Research Group
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& Donders Institute for Brain Cognition and Behaviour - Nijmegen

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Neurologist University Medical Centre - Maastricht

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Euro-DyMA: Federation of European Myotonic Dystrophy Associations
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VAN GENT JORG

MD Nederland

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COURSE VENUE

mbw Medienberatung der Wirtschaft GmbH - Munich
Max-Joseph-Straße 5, 80333 Munich, Germany

Industry Representative Attendance Policy

The event is designed primarily for healthcare providers (HCPs) involved in the diagnosis and management of myotonic dystrophy type 1 (DM1), as well as researchers and other professionals seeking to expand their knowledge in this field.

While this event is not specifically tailored to industry representatives, we welcome individuals from companies who wish to attend in a non-promotional capacity to learn and engage with the educational content.

Unrestricted educational grant

Organizing Secretariat and Provider ECM 362



First Class srl - Meetings and Conferences
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14-15 April 2025
Munich, Germany

mbw Medienberatung der
Wirtschaft Munich, Germany

Euro DM CRN

**Kick-off Meeting
of the European
Clinical Research Network
for Myotonic Dystrophies**

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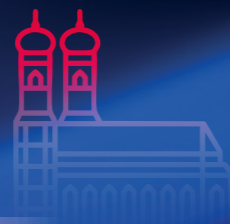
OVERARCHING OBJECTIVES

Facilitate clinical trial implementation across Europe by creating a unified and collaborative framework.

Contribute to the US-based DM-CRN DM1 natural history database to deepen understanding of disease progression and support research worldwide.

Enhance collaboration among European DM experts, fostering knowledge and resource sharing.

Standardize research and clinical protocols to improve outcomes for DM patients across Europe.



Programme 14th April 2025

- 12:00 - 12:30 Welcome and Introduction: On behalf of the kick-off organizing working group
Benedikt Schoser
- 12:30 - 13:00 European landscape on DM
A patient organization view
Alain Geille
- 13:00 - 13:30 The MDF perspective
Andy Rohrwasser
- 13:30 - 13:45 Q&A
- 13:45 - 14:30 Lunch Break
- 14:30 - 15:00 Update on the END-DM-CRN network USA
Valeria Sansone
- 15:00 - 15:15 DM Registries with focus on the DM Scope
Guillaume Bassez
- 15:15 - 15:30 UK DM registry
Christopher Turner
- 15:30 - 15:45 Italian DM working group
Gabrielle Siciliano
- 15:45 - 16:00 Euro-ERN registry: an overview
Antonio Atalaia
- 16:00 - 16:15 Q&A
- 16:15 - 16:30 Coffee Break
- 16:30 - 17:00 Global DM-CRN
Nickolas Johnson
- 17:00 - 17:30 New natural history study in DM1 for myotonia assessments
Jean-Yves Hogrel
- 17:30 - 17:45 Training the new generation of DM experts: the ENTRY-DM doctoral network
Mario Gomes-Pereira
- 17:45 - 18:00 Q&A

15th April 2025

- 09:00 - 09:15 Introduction day 2:
On behalf of the kick-off organizing working group
Benedikt Schoser
- 09:15 - 09:45 PROMs and PROs the Maastricht experience
Karin Faber
- 09:45 - 10:15 Congenital DM - an overview on current trials
Hilde Brackman
- 10:15 - 10:45 Project ANIQ
Jorg van Gent
- 10:45 - 11:00 Q&A
- 11:00 - 11:15 Coffee Break
- 11:15 - 11:30 DM2 Registry an overview
Stanislav Vohanka
- 11:30 - 13:00 Industry perspectives
Presentations and Round table discussion
Discussion moderated by Benedikt Schoser
- 13:00 - 13:45 Alignments of new clinical trial centres to Global DM-CRN
Open Discussion on the needs
- 13:45 - 14:00 Next steps and next meeting
Benedikt Schoser
- 14:00 - 15:00 Lunch and Fairwell

