

SCIENTIFIC PROGRAM

NOVEMBER 30TH • DECEMBER 1ST 2023 • 2nd edition

TRAILS 2023

**ALPHA MANNOSIDOSIS AND MUCOPOLYSACCHARIDOSIS:
OPTIMIZING PATIENT JOURNEYS**

MADRID

Meliá Madrid Serrano
Calle de Claudio Coello, 139 – Madrid

08.20 – 08.30 Introduction and meeting objectives – *C. Lampe*

SESSION 1 – FOCUS ON EARLY DIAGNOSIS IN LSDs

Early diagnosis in LSDs

08.30 – 09.00 Early diagnosis in MPS and AM: rationale and barriers in practice – *C. Lampe*

09.00 – 09.30 Learning from mistakes: 40 years of experience – *D. Malm*

09.30 – 10.00 Algorithm for early diagnosis: optimization and practical application – *N. Guffon*

The role of the MDT in early diagnosis

10.00 – 10.20 Increase diagnosis by multidisciplinary collaboration – *F. Lagler*

Genetic matters

10.20 – 10.40 How genotype influences disease phenotype – *L. Borgwardt*

10.40 – 11.00 Mild forms in AM: barriers in early diagnosis (case collection) – *K. Stepien*

11.00 – 11.10 DISCUSSION

11.10 – 11.30 Coffee Break

SESSION 2 – FOCUS ON PATIENT

Patient management

11.30 – 12.00 To treat or not to treat: Precision medicine in MPS and AM early, mild and severe forms – (*Introduction – M. Magner*)

Bone marrow transplant + Pre- and post-transplant treatment in AM and MPS – *M. Magner*

12.00 – 12.30 Immunological aspects – impact on vaccinations/antibiotics use – *D. Malm*

12.30 – 13.00 Drug holidays or treatment discontinuation – *N. Guffon*

13.00 – 14.00 Lunch

Patient management

14.00 – 14.30 Treatment outcome evaluation – *D. Zafeiriou*

14.30 – 15.00 Sparkle Registry – *C. Lampe*

The role of the MDT in patient's management

15.00 – 15.30 Improving patients' management – (hearing impairment and impact on QoL – speech impact: hearing aids) – *C. Gadepalli*

15.30 – 16.00 Improving patients' management – (mobility issues: medical walking aids, surgery eligibility, orthopedic surgeon, etc) – *I. Boutros*

16.00 – 16.10 DISCUSSION

16.10 – 16.30 Coffee Break

Sharing best practice

16.30 – 17.00 Promoting referral – experience from Portugal – *C. Macario*

17.00 – 17.30 MPS/AM Diagnostic pathway – experience in Taiwan – *S. Pei Lin*

17.30 – 18.00 MDT patient management – experience in Netherlands – *C. Lampe*

DECEMBER 1ST 2023

08.20 – 08.40 Introduction and key messages of day 1 – *C. Lampe*

SESSION 3 – FOCUS ON COMMUNICATION

Fostering communication in medicine

08.40 – 09.40 HCP-Patient/parents communication – *A. Tedone*

09.40 – 10.30 Telemedicine and remote communication – Proper use and how to take the most out of them – *K. Stepien*

On patients' side

10.30 – 11.00 The patients' voice – *J. Cruz*

11.00 – 11.30 *DISCUSSION*

11.30 – 11.50 *Coffee Break*

SESSION 4 – FOCUS ON CLINICAL PRACTICE

Clinical case discussion (break-out rooms)

11.50 – 12.20 Drug discontinuation – *A. Hermida*

12.20 – 12.50 Positive psychological impact of therapy – *F. Al Jasmi*

12.50 – 13.20 Bone marrow transplant – *B. Burton*

13.20 – 13.50 Late onset disease: diagnosis and treatment in adult life – *I. Bruno*

13.50 – 14.40 Conclusions and Take-Home messages

14.40 *Lunch*



FACULTY

Al Jasmi Fatma – (United Arab Emirates)

Borgwardt Line – (Denmark)

Boutros Ihab – (United Kingdom)

Bruno Irene – (Italy)

Burton Barbara – (USA)

Cruz Jordi – (Spain)

Gadepalli Chaitanya – (United Kingdom)

Guffon Nathalie – (France)

Hermida Alvaro – (Spain)

Lagler Florian – (Austria)

Lampe Christina – (Germany)

Lin Shuan-Pei – (Taiwan)

Macario Carmo – (Portugal)

Magner Martin – (Czech Republic)

Malm Dag – (Norway)

Stepien Karolina – (United Kingdom)

Tedone Amanda – (Italy)

Zafeiriou Dimitrios – (Greece)

STEERING COMMITTEE

Lagler Florian – Salzburg (Austria)

Lampe Christina – Giessen (Germany)

Magner Martin – Prague (Czech Republic)

Malm Dag – Tromso (Norway)

Stepien Karolina – Manchester (United Kingdom)

Zafeiriou Dimitrios – Thessaloniki (Greece)

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OFFICIAL LANGUAGE: The official language is English.



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