

EAMDA 47th Annual General Assembly

Czech Republic, September 20 – 23, 2018 (Clarion Congress Hotel, Prague 190 00, Freyova 33)

Thursday, September 20th, 2018

Until 15:00 Arrival of Delegates / Transport from airport

16:00 - 17:00 Registration

17:30 - 19:00 Executive Committee Meeting (members only)

19:30 - 21:30 **Welcome speeches and Dinner**

Friday, September 21st, 2018

8:00 Registration

8:30 - 9:00 **Official opening**

Official Speeches

Tomislav Goll in memoriam of Boris Sustarcic; President of EAMDA: Tadej Korosec; President of AMD: Zdenek Janda
MUDr. Radim Mazanec, PhD. Representative of the Czech Neurological Society - Neuromuscular Section

A) MEDICAL PART

I) Session title: **Diagnosis and new therapies in NMD**

9:00 - 9:15 **Emerging treatments for ALS - solutions or problems?**

Blaz Koritnik

Institute of Clinical Neurophysiology, University Medical Centre Ljubljana

9:15 - 9:30 **Genetics therapy in DMD**

Lenka Juříková

University Hospital, Brno

9:30 - 9:45 **Benefits of magnetic resonance in diagnosis of NMD**

Livie Mensová

Motol University Hospital, Prague

9:45 - 10:00 **Advances In the Diagnosis And Management of Neuromuscular Disorders in Childhood**

Jana Haberlová

Motol University Hospital, Prague

10:00 - 10:15 **Pain in muscular dystrophy**

Olesja Parmová

University Hospital Brno

II) Session title: **New clinical trials and approach in NMD**

10:15 - 10:30 **FSH muscular dystrophy – variability of clinical presentation**

Davorka Vranjes

Department of Neurology, University Hospital Center Zagreb, Croatia

10:30 - 10:45 **LGMD**

Radim Mazanec

Motol University Hospital, Prague

10:45 - 11:15 **Coffee break**

11:15 - 11:30 **The importance of registries and biobanking for promoting diagnosis and research in RD. The RD-Connect experience.**

Anna Ambrosini

Fondazione Telethon Research & Development office, Milan, Italy

11:30 - 11:45 **Pushing boundaries to help all SMA patients - update on the risdiplam program**

Ksenija Gorni

Translational Medicine Leader - Rare Diseases, Roche Pharma Research

11:45 - 12:00 **Therapeutic experience in SMA type II and III**

Giacomo Comi

Department of Neurology, Policlinico Hospital, University of Milan

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- 12:00 - 12:15 **Impact of multidisciplinary care in neuromuscular disease: ALS Centre Ljubljana**
Polona Klavzar
Institute of Clinical Neurophysiology, University Medical Centre Ljubljana
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- 12:15 - 12:30 **Factors influencing participation in patients with neuromuscular disease**
Ales Praznikar
Institute of Clinical Neurophysiology, University Medical Centre Ljubljana
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- 12:30 - 12:45 **Whether the role of symptomatic therapy has changed in the era of new therapeutic possibilities for NMD**
Gordana Kovacevic
Mother and child health Institute "Dr Vukan Cupic" Belgrade, Serbia

12:45 - 13:45 **Plenary debate**

13:45 - 15:15 **Lunch**

III) Session title: Cardiological and respiratory care

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- 15:15 - 15:30 **Cardiological care at boys with DMD**
Martin Peřl (Doc. Pacovský)
University Hospital Brno
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- 15:30 - 15:45 **Mechanical ventilation for patients with neuromuscular disease in Slovenia**
Patricija Kranjc, Polonca Klinar
Institute of Clinical Neurophysiology, University Medical Centre Ljubljana
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- 15:45 - 16:00 **Invasive ventilation**
Stefan Popov
Pulmonologist/Member of the Bulgarian Association for Neuromuscular Diseases
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- 16:00 - 16:15 **Mouthpiece ventilation and non invasive pulmonary ventilation in DMD**
Vilém Novák
University Hospital Ostrava

16:15 - 16:45 **Coffee break**

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- 16:45 - 17:00 **The newest trends in pulmonary ventilation in DMD**
David Kemlink
General University Hospital in Prague
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- 17:00 - 17:15 **Respiratory physiotherapy prevention of lung complications in individuals with SMA**
Libuře Smolíková
University Hospital Motol Prague
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17:15 - 18:15 **Plenary debate**

19:00 - 21:00 **47th Annual General Assembly meeting (members only)**

21:00 **Dinner**

Saturday, September 22nd, 2018

IV) Session title: Restorative rehabilitation and treatment

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- 9:00 - 9:20 **Orthopedics care at youth and children with NMD**
Petr Krawczyk
President of Czech orthopedic society
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- 9:20 - 9:40 **Respiratory care for persons with neuromuscular disorders**
řesták Jakub
Czech Republic
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- 9:40 - 10:00 **Nutritional aspects of neuromuscular disorders**
Pavel Kohout
Thomayer Hospital Prague
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10:00 - 10:30 **Plenary debate**

10:30 - 11:00 **Coffee break**

B) SOCIAL PART

11:00 - 11:20 **Partnerships for Progress in Neurology**

Dona Walsh, Executive Director
EFNA

11:20 - 11:40 **EURORDIS: a European united voice for rare disease patients**

Alexandre Mejat
EURORDIS

11:40 - 12:00 **How can a patient organization accelerate the accessibility of a newly registered treatment?**

Václav Hradilek
Smaci

12:00 - 12:20 **The role of patient organizations in the NMD patient's life and his family**

Andrea Madunová
MDA of Slovakia

12:20 - 12:40 **Media representation of people with NMD in Bulgaria**

Jana Popova
MDA of Bulgaria

12:40 - 13:00 **Patient engagement at EMA and EPF activities**

Michal Rataj
MDA of Poland

13:00 - 13:30 **Plenary debate**

13:30 - 15:00 **Lunch**

15:00 - 16:30 **Round table/Workshop: Experiences of different treatments in SMA**

Marica Miric
President MDA of Croatia

19:00 **Gala dinner**

Sunday, September 23rd, 2018

9:00 - 10:30 **Executive Committee Meeting (members only)**

Departure of Participants / Transport to airport

PARTNER:

SUPPORTERS:

