

## 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

**Official opening and speeches**

8:30 - 9:00 Zdenek Janda, President of AMD; Boris Sustarsic, President of EAMDA

**A) MEDICAL PART**

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

**Section chairperson: <to be announced>**

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 **<title to be announced>**

Stanislav Voháňka

University Hospital, Brno

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

**Section chairperson: <to be announced>**

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 **<title to be announced>**

Fumi Takeuchi

Newcastle University, UK

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

11:15 - 11:30 **LGMD**

Radim Mazanec

Motol University Hospital, Prague

11:30 - 11:45 **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

11:45 - 12:00 **<title to be announced>**

Ksenija Gorni

Translational Medicine Leader - Rare Diseases, Roche Pharma Research



12:00	-	12:15	<b>Therapeutic experience in SMA type II and III</b> Giacomo Comi Department of Neurology, Policlinico Hospital, University of Milan
12:15	-	12:30	<b>Impact of multidisciplinary care in neuromuscular disease: ALS Centre Ljubljana</b> Polona Klavzar Institute of Clinical Neurophysiology, University Medical Centre Ljubljana
12:30	-	12:45	<b>Factors influencing participation in patients with neuromuscular disease</b> Ales Praznikar Institute of Clinical Neurophysiology, University Medical Centre Ljubljana
12:45	-	13:00	<b>Whether the role of symptomatic therapy has changed in the era of new therapeutic possibilities for NMD</b> Gordana Kovacevic Mother and child health Institute "Dr Vukan Cupic" Belgrade, Serbia
13:00	-	14:00	<b>Plenary debate</b>
14:00	-	15:30	<b>Lunch</b>
<b>III) Session title: Cardiological and respiratory care</b>			
<b>Section chairperson: &lt;to be announced&gt;</b>			
15:30	-	15:45	<b>Cardiological care at boys with DMD</b> Martin Peřl (Doc. Pacovský) University Hospital Brno
15:45	-	16:00	<b>Mechanical ventilation for patients with neuromuscular disease in Slovenia</b> Patricija Kranjc, Polona Klinar Institute of Clinical Neurophysiology, University Medical Centre Ljubljana
16:00	-	16:15	<b>Invasive ventilation</b> Stefan Popov <institution to be announced>
16:15	-	16:30	<b>Mouthpiece ventilation and non invasive pulmonary ventilation in DMD</b> Vilém Novák University Hospital Ostrava
16:30	-	17:00	<b>Coffee break</b>
17:00	-	17:15	<b>The newest trends in pulmonary ventilation in DMD</b> David Kemlink General University Hospital in Prague
17:15	-	17:30	<b>Respiratory physiotherapy prevention of lung complications in individuals with SMA</b> Libuře Smolíková University Hospital Brno
17:30	-	18:30	<b>Plenary debate</b>
19:00	-	21:00	<b>47th Annual General Assembly meetig (members only)</b>
21:00			<b>Dinner</b>

**Saturday, September 22nd, 2018**

**IV) Session title: Restorative rehabilitation and treatment**

**Section chairperson: <to be announced>**

9:00 - 9:20 **Orthopedics care at youth and children with NMD**

Petr Krawczyk

President of Czech orthopedic society

9:20 - 9:40 **<title to be announced>**

Alexandre Mejat

EURORDIS

9:40 - 10:00 **Nutritional aspects of neuromuscular disorders**

Pavel Kohout

Thomayer Hospital Prague

10:00 - 10:30 **Plenary debate**

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

**B) SOCIAL PART**

**Section chairperson: <to be announced>**

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

Dona Walsh, Executive Director

EFNA

11:20 - 11:40 **Respiratory care for persons with neuromuscular disorders**

Šesták Jakub

<institution to be announced>

11:40 - 12:00 **<title to be announced>**

<lecture to be announced>

SMA Czech Republic

12:00 - 12:20 **<title to be announced>**

<lecture to be announced>

MDA of Slovakia

12:20 - 12:40 **<title to be announced>**

<lecture to be announced>

Jana Popova, Bulgaria

12:40 - 13:00 **<title to be announced>**

<lecture to be announced>

Michal Rataj, Poland

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

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

**Section chairperson: Marica Milic, President MDA of Croatia**

15:00 - 16:30 **Round table/Workshop: Different experiences of Spinraza treatment in SMA**

Marica Miric

President MDA of Croatia

**Sunday, September 23rd, 2018**

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

Departure of Participants / Transport to airport

**PARTNERS:**

