

EAMDA 46th Annual General Assembly

Zagreb, October 14th, 2017 (Hotel Holiday Zagreb, Jankomir 27, 10090 Zagreb)

Official opening and speeches (conference hall "HOLIDAY")

7:30 - 8:00 Registration of delegates

8:00 - 8:30 Marica Miric, President of MDA of Croatia; Zorislav Bobus, MD, President of SOIH
Boris Sustarsic, President of EAMDA

I) MEDICAL PART (conference hall "HOLIDAY")

Section chairperson: prof. dr. sc. Nina Barisic

8:30 - 8:45 **Proxymal SMA-standards of care in pedatric age group and emerging therapeutic strategies**
prof. Nina Barisic, MD, PhD
University Clinical Hospital Centre Zagreb, Croatia

8:45 - 9:00 **SMA and SMN-Related SMA variants in Adults**
prim. Davorka Vranjes, MD
University Clinical Hospital Centre Zagreb, Croatia

9:00 - 9:15 **Biogen update**
Caroline Daly, Senior Manager, Public Affairs, Patient Advocacy
Biogen International GmbH, Zug, Switzerland

9:15 - 9:30 **Treatment of SMA patients with nusinersen: the Slovenian experience**
Damjan Osredkar, MD, PhD
Head of the Dpt. of Pediatric Neurology, University Children's Hospital Ljubljana, Slovenia

9:30 - 9:45 **Pompe disease**
Danijela Petkovic Ramadza, MD
University Clinical Hospital Centre Zagreb, Croatia

9:45 - 10:00 **New perspectives in DMD management**
Dr. Sunay Ozdas, Regional Medical Head of CEE & MENA & APAC PTC Therapeutics
PTC Therapeutics, Zug, Switzerland

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

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

Chairperson: prim. Davorka Vranjes, MD

11:00 - 11:15 **Myozyme program & treatment**
SANOFI, Croatia

11:15 - 11:30 **Nutrition considerations in NMD**
Prim. dr. Gordana Kovacevic MSc, Pediatric neurologist
Mother and child health care Institute, Belgrade, Serbia

11:30 - 11:45 **Different healthcare in different countries for patients with ALS/MND**
Assist.Prof. Ales Praznikar, MD MSc; neurologist, rehab. med. specialist
Head of Department for Neurorehabilitation, UMC Ljubljana, Slovenia

11:45 - 12:00 **Muscle biopsy in the area of exome and transcriptome sequencing**
Mija Meznaric Assistant Professor, MD, PhD
University of Ljubljana, Medical Faculty Institute of Anatomy, Ljubljana, Slovenia

12:00 - 12:15 **Teenlifting: electrostimulation of muscles**
dr. Sanja Malbasa Gosovic
TEENLIFTING d.o.o., Zagreb, Croatia

12:15 - 12:30 **Teenlifting: an example of rehabilitation - person with SMA**
Tea Černigoj Pušnjak, MSc, Ljubljana, Slovenia

12:30 - 13:00 **Plenary debate**

13:00 - 14:30 **Lunch**

II) SOCIAL PART (conference hall "HOLIDAY")

14:30 - 15:00 **The biggest challenges and obstacles for people with NMD in Bulgaria**

Jana Popova, Bulgaria

15:00 - 15:30 **Experience with Spinal Muscular Atrophy type 1**

Ana Alapic and Mate Beslic, Croatia

15:30 - 16:00 **Experience with Spinal Muscular Atrophy type 2**

Stella Franjic, Croatia

16:00 - 16:30 **Experience with Duchenne Muscular Dystrophy (Nonsense mutation)**

Andrea Ruzic and Pavao Ruzic, Croatia

16:30 - 17:00 **Plenary debate**

III) ADMINISTRATIVE PART (conference hall "ZAGREB"):

17:00 - 19:00 **46th Annual General Assembly (representatives of member associations only)**

Agenda is going to be presented on the meeting

19:00 - **Dinner**

FRIENDS OF THE CONFERENCE

