

Times are expressed as Central European Time – CET.

EAMDA online International conference on neuromuscular disorders

October 15th & 16th, 2021

MEDICAL DAY - Friday, October 15th, 2021

9:45 - 10:00 **Official opening & brief review of current EAMDA activities**, Tadej Korosec, EAMDA president

Morning session

10:00 - 10:30 **Biomarkers and the Development of a Precision Medicine Approach in SMA**

Milos Brkusanin, PhD, Research Associate

Centre for Human Molecular Genetics, University of Belgrade - Faculty of Biology

10:30 - 11:00 **Nutrition, diet and life style in patients with SMA**

Kohout Pavel MUDr., doc., Ph.D.

Thomayer University Hospital, Prague

11:00 - 11:30 **How to navigate the changing seas of SMA treatment**

Assoc. Prof. Damjan Osredkar, MD, PhD

University Children's Hospital Ljubljana

11:30 - 12:00 **Adult SMA patients treatment in Croatia - our experiences**

Prof. Ervina Bilic, MD. PhD., neurologist

Department of Neurology Clinical Hospital Center Zagreb, University of Zagreb School of Medicine

12:00 - 12:30 **Home Mechanical Ventilation in Patient with Neuromuscular Diseases**

Dr. Milan Rodic

Mother And Child Health Care Institute of Serbia „Dr Vukan Cupic“, Serbia

12:30 - 12:45 **Conclusion by moderator**

12:45 - 13:30 **Lunch break 45 min**

Afternoon session

13:30 - 14:00 **The Czech National Registry of DMD/BMD**

Lenka Jirikova

University Hospital Brno University Hospital Brno

14:00 - 14:30 **Limb-girdle muscular dystrophies - subtypes and care standards**

Dr. Anna Macias

The Department of Cardiology and Neurology Medical University of Warsaw

14:30 - 15:00 **Myasthenia gravis: learning immunopathogenesis via therapeutic intervention?**

Prof. Heinz Wiendl, MD

Institute of Translational Neurology, University of Münster, Germany

15:00 - 15:30 **Updates from TREAT-NMD and TGDOC registries**

Anna Ambrosini, Fondazione Telethon, Milan Italy and TREAT-NMD TGDOC Chair

Fondazione Telethon, Milan, Italy and TREAT-NMD

15:30 - 16:00 **Charcot-Marie-Tooth disease: experience from a Romanian neuromuscular center**

Raluca Teleanu, Daniela Vasile, Diana Epure, Oana Vladacenco

Dr. V Gomoiu Children's Hospital Bucharest Romania

16:00 - 16:15 **Conclusion by moderator**

Online EAMDA International Conference on NMD 2021:

Medical day: October 15th, 2021; Social day: October 16th, 2021

Satellite Symposium 2021

October 15th, 2021 at 17:00 CET

Registration deadline for attendees:

October 11th, 2021

REGISTER NOW -> <https://eamda-ic2021.eu/>



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17:00 - 19:00	Satellite symposium (pharma & experts, on invitation only)
	Newborn screening in general & EU experiences Asst. Prof. Urh Groselj, MD, PhD University Children's Hospital Ljubljana
	Newborn screening for SMA – challenges and potential benefits Assoc. Prof. Damjan Osredkar, MD, PhD University Children's Hospital Ljubljana

SOCIAL DAY - Saturday, October 16th, 2021

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Breakout session: Personal assistance

10:00 - 11:00	Personal assistance & independent living in different countries -interactive talk on personal assistance, independent living, experiences
11:00 - 11:10	Brainstorming break

Different NMD social presentations

11:10 - 11:40	OneNeurology Partnership Donna Walsh EFNA
11:40 - 12:10	Empowerment of people with ALS Andreja Sustar Muscular dystrophy association of Slovenia
12:10 - 12:55	Lunch break 45 min
12:55 - 13:25	Adult patients with neuromuscular disease - view of patients and caregivers David Petrasek Czech Republic
13:25 - 13:55	An organisation run by and for people with neuromuscular conditions Dr Jon Rey-Hastie Pathfinders, United Kingdom
13:55 - 14:05	Brainstorming break
14:05 - 14:35	Presentation of ECMTF and their activities on the European level Arabela Acalinei European CMT Federation (ECMTF), Board Member
14:35 - 15:05	Components of independent living for persons with neuromuscular diseases Marica Miric, SDDH president Croatian Muscular Dystrophy Association (SDDH)
14:35 - 14:50	Conclusion by moderators

17:00 - 19:00 49th Annual General Assembly meeting (EAMDA member representatives only)

OUR SUPPORTERS AND FRIENDS

