



Medical part of the conference: Grand hotel Union, Ljubljana, Slovenia
Administrative tasks and a social part of the program: City Hotel Ljubljana, Slovenia

Thursday, September 25th, 2014 (City Hotel Ljubljana, Slovenia)

Until 12.00 Arrival of Delegates / Transport from airport
15.00 – 17.00 1st Executive Committee Meeting (members only)
17.00 – 19.00 Informal individual meetings
19.00 – 21.00 Dinner

Friday, September 26th, 2014 (Grand hotel Union, Ljubljana, Slovenia)

08.00 – 08.30 Official opening and speeches
acad. prof. dr. Tadej Bajd, President of the Slovenian Academy of Sciences and Arts
prof. dr. Dušan Šuput, Dean of Faculty of Medicine, University of Ljubljana
Minister of Health
Minister of Labour, Family, Social Affairs and Equal Opportunities
Boris Šuštaršič, President of MDA of Slovenia

A) MEDICAL PART OF THE CONFERENCE

I. Diagnostics and epidemiology of NMD

Chairperson: **assist. dr. Lea Leonardis, Institute of Clinical Neurophysiology**

08.30 – 08.50 Epidemiology
prof. dr. Janez Zidar, Institute of Clinical Neurophysiology

08.50 – 09.10 Genetic diagnostics of the prevalence of various forms of NMD in Slovenia
doc. dr. Luca Lovrečič, Institute of Medical Genetics,
University Medical Centre Ljubljana

09.10 – 09.30 Muscle biopsy in diagnostics of NMD diseases
assist. prof. Marija Meznarič, Institute of Anatomy, Faculty of Medicine,
University of Ljubljana

09.30 – 09.50 Clinical neurophysiology of progressive NMD
prof. dr. Simon Podnar, Institute of Clinical Neurophysiology

09.50 – 10.30 Plenary debate

10.30 – 11.00 Coffee break

II. Assessment of neuro-muscular functions

Chairperson: **assist. prof. Marija Meznarič, Institute of Anatomy, Faculty of Medicine, University of Ljubljana**

11.00 – 11.20 Biomechanical evaluation of neuro-muscular functions
assoc. prof. dr. Nejc Šarabon, University of Primorska, Andrej Marušič Institute,
Department of Health Study, Koper, Slovenia

11.20 – 11.40 Morphometry of disused and used skeletal muscle fibers
prof. Ugo Carraro, Department of Biomedical Science, University of Padova

11.40 – 12.00 Plenary debate



III. Assistive technology and NMD

Chairperson: acad. prof. dr. Milan R. Dimitrijević, MD, D.Sc, Houston, Vienna, Ljubljana

12.00 – 12.20 **What electrical stimulation can do for persons with NMD?**

dr. Winfried Mayr, Center for Medical Physics and Biomedical Engineering,
Vienna Medical University

12.20 – 12.40 **Clinical effects of the exercise therapy in Amiotrophic Lateral Sclerosis patients**

Dr. Antonio Merico, Centro Unico Prenotazioni, Ospedale San Camillo IRCCS,
Lido di Venezia

12.40 – 13.00 **When will robots enable persons with NMD to walk?**

prof. dr. Marko Munih, Faculty of Electrical Engineering, University of Ljubljana

13.00 – 13.20 **How to live a full life with NMD – technological support**

prof. dr. Anton Zupan, University Rehabilitation Institute, Republic of Slovenia

13.20 – 14.00 **Plenary debate**

14.00 – 16.00 **Lunch break**

IV. Maintenance of altered capabilities, restorative rehabilitation and treatment

Chairperson: prof. dr. Anton Zupan, University Rehabilitation Institute,
Republic of Slovenia

16.00 – 16.20 **ALS treatment**

asist. dr. Blaž Koritnik, Institute of Clinical Neurophysiology,
University Medical Centre Ljubljana

16.20 – 16.40 **Structural affected and non-affected neuromuscular tissue**

prof. Ugo Carraro, Department of Biomedical Science, University of Padova

16.40 – 17.00 **EUROMAC a European registry for McArdle Disease**

dr. Ros Quinlivan, MBBS, DCH, FRCPCH, FRCP, MD
MRC Centre for Neuromuscular Disease
National Hospital for Neurology and Neurosurgery, Queen Square AND Great
Ormond Street Hospital

17.00 – 17.20 **Treatment of neuromuscular disorders**

asist. dr. Lea Leonardis, Institute of Clinical Neurophysiology,
University Medical Centre Ljubljana

17.20 – 17.40 **Translarna (Ataluren) for nonsense mediated Duchenne Muscular Dystrophy**

dr. Ros Quinlivan, MBBS, DCH, FRCPCH, FRCP, MD
MRC Centre for Neuromuscular Disease
National Hospital for Neurology and Neurosurgery, Queen Square AND Great
Ormond Street Hospital

17.40 – 18.00 **Procedures in restorative neurology of NMD**

acad. prof. dr. Milan R. Dimitrijević, MD, D.Sc, Houston, Vienna, Ljubljana

18.00 – 18.20 **Maintenance of biological potentials of people with NMD in Rehabilitation Center Dom dva topola, Izola**

Boris Šuštaršič, MDA of Slovenia
prof. dr. Anton Zupan, University Rehabilitation Institute, Republic of Slovenia
Aleša Kloosterwaard, Rehabilitation Center Dom dva topola, Izola

18.20 – 18.30 **Summary**

Boris Šuštaršič, MDA of Slovenia

18.30 – 19.30 **Plenary debate**

19.30 **Dinner**



Saturday, September 27th, 2014 (Silver saloon in Grand hotel Union, Ljubljana, Slovenia)

10.00 – 12.00 *Round-table discussion of the science of progressive neuromuscular disorders*

(experts and people with NMD by invitation)

Chairpersons: prof.dr. Dimitrijević, prof.dr. Zidar and prof.dr. Zupan

Saturday, September 27th, 2014 (City Hotel Ljubljana, Slovenia)

B) SOCIAL PART OF THE CONFERENCE

08.30 – 10.30 *44th Annual General Meeting*

(representatives of member associations only)

Agenda is going to be presented on the conference

Social entities for people with NMD

Chairperson: Dona Jandova, EAMDA vice president, MDA of Czech Republic

10.30 – 13.00 Workshop on “Living with neuromuscular disorders and its social aspects”

13.00 – 15.00 Lunch

15.00 – 16.30 Trip to Rehabilitation center Dom dva topola, Izola (on the Adriatic Sea)

16.30 – 18.00 Presentation of Rehabilitation programs for people with NMD in Dom dva topola
prof. dr. Anton Zupan, University Rehabilitation Institute, Republic of Slovenia
Darinka Zagoršek, Business organizer, Rehabilitation Center Dom dva topola, Izola

18.00 – 18.30 Discussions

19.00 – 21.00 Dinner and later return to Ljubljana

Sunday, September 28th, 2014

09.00 – 10.30 2nd Executive Committee Meeting (EC members only)

Departure of Participants / Transport to airport