



eamda

40th Annual General Meeting

Milan, September 16-18, 2010

ATA Hotel Expo Fiera Via Keplero, Pero (Milan), Italy

Thursday, September 16th, 2010

Arrival of Delegates / Transport from airport

15.00 – 17.00 Registration

Visits to the NEMO clinic

17.30 – 19.00 Executive Committee Meeting (members only)

19.30 – 21.00 *Welcome and Dinner*

Friday, September 17th, 2010

Morning session

8.45 – 9.30

Opening and welcome speeches

President of EAMDA, Boris Sustarsic

President of UILDM, Alberto Fontana

Chairperson of the UILDM Milan branch, Marco Rasconi

Authorities

I. An eye on the cure and the care

Chairpersons: Massimo Corbo (Milan, Italy) and Tiziana Mongini (Turin, Italy)

9.30 – 9.50

The Italian Telethon investment in neuromuscular research

Anna Ambrosini, Fondazione Telethon, Milan, Italy

9.50 – 10.10

New treatments and clinical trials for neuromuscular disorders

Janberndt Kirschner, University of Freiburg, Germany

10.10 – 10.30

Managing respiratory problems in people with NMDs

Andrea Vianello, University of Padua, Padua, Italy

10.30 – 10.50

Neurocontrol of the locomotion in progressive neuromuscular diseases

Ales Praznikar, University Medical Centre Ljubljana, Ljubljana, Slovenia

10.50 – 11.10

Fitness for people with neuromuscular disorders

Marion Main, Great Ormond street Hospital for Children, London, UK

11.10 – 11.30

General discussion

11.30 – 12.00 *Coffee break*



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- 12.00 – 13.00 The neuromuscular clinical centres: a person – centered approach
- The Rehabilitation Centre for Neuromuscular Diseases, Research Unit
Jes Rahbek, Aarhus, Denmark
 - The NeuroMuscular Omnicentre (NEMO)
Massimo Corbo, Milan, Italy

13.00 – 15.00 Lunch

Afternoon session

II. Communication and alliances within Associations

Chairpersons: **Jes Rahbek (Aarhus, Denmark) and Maryze Schoneveld van der Linde (Baarn, The Netherlands)**

- 15.00 – 15.20 Quality of Life Questionnaires – powerful tools for assessing treatments and needs of people with NMD
Valeria Sansone, University of Milan, Milan, Italy
- 15.20 – 15.40 Ethical aspects of the use of assistive technology
Anton Zupan, University Rehabilitation Institute, Ljubljana, Slovenia
- 15.40 – 16.10 Communication and empowerment of people with a NMD
Follow up from the Treat-NMD Communication meeting
Jes Rahbek, Aarhus, Denmark
John Marquardt Aarhus, Denmark
Maryze Schoneveld van der Linde, ENMC, Baarn, The Netherlands
- 16.10 – 16.30 Bringing power to the next generation – the Trailblazers campaigning initiative
Marita Pohlschmidt, Muscular Dystrophy Campaign, London, UK
- 16.30 – 16.50 UILDM - Strength through Unity
Cira Solimene, UILDM General Manager, Naples, Italy
- 16.50 – 17.30 General discussion
- 19.30 – 21.00 *Gala Dinner (dedicated to 40th Anniversary of EAMDA)*



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Saturday, September 18th, 2010

III. People with neuromuscular disorders as equal citizens

Chairperson: Tomislav Goll (Croatia)

- 09.00 – 09.15 Introduction remarks, *Tomislav Goll, MDA of Croatia*
- 09.15 – 09.30 Social and biological perspectives of people with NMD
Boris Sustarsic, President of EAMDA
- 09.30 – 09.45 Holistic concept of disability organization of people with NMD
Jan Jakobsen, Muskelsvindsfonden, Denmark
- 09.45 – 10.00 Social integration and equal life of people with NMD
Maria Duracinska and Silvia Petruchova, MDA of the Slovak Republic
- 10.00 – 10.15 Active role as live style
Ivanka Jovanovic, MDA of Serbia
- 10.15 – 10.30 Essential role of personal assistance for people with NMD
Tadej Korosec, MDA of Slovenia
- 10.30 – 11.00 *Coffee break*
- 11.00 – 11.15 Mentoring. Participation in the EU 2007-2013 initiative “Youth in action”
Massimo Guitarrini, UILDM, Rome, Italy
- 11.15 – 11.30 Social dimensions of EAMDA Youth camp 2010 in Medulin, Croatia
Tomislav Goll, MDA of Croatia
- 11.30 – 11.45 Social activities of people with NMD
Iztok Mrak, MDA of Slovenia
- 11.45 – 12.30 Discussion and Closing remarks
- 12.30 – 14.00 *Lunch*
- 14.00 – 16.00 EAMDA 40th ANNUAL GENERAL MEETING (delegates only)
Visits to NEMO Clinic
- 20.00 – 21.30 *Dinner*

Sunday, September 19th, 2010

- 09.30 – 11.00 Executive Committee Meeting
- Departure of Participants/Transport to airport