



eamda

41st Annual General Meeting

Prague, September 8-11, 2011

Clarion Hotel, Prague, Czech Republic



Thursday, September 8th, 2011

- 'till 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 9th, 2011

Morning session

- 7.30 – 8:45 *Breakfast*
- 9.00 – 9.30 **Official opening and speeches**
President of EAMDA, Boris Šuštaršič
President of AMD, Zdeněk Janda

I. The medical assessment of people with neuromuscular disorders

Chairpersons: Petr Procházka, Ivanka Jovanovič, Zdeněk Janda, Andrea Madunová,

- 9.30 – 9.50 Vohánka S., Ošlejšková H, Rusnáková Š, Večeřa L, Hlavatá J, Lukacs Z (Czech Republic)
Screening for adults of Pompe disease in Czech population: results and edification
- 9.50 – 10.10 Večeřa L, Vohánka S, Mazanec M, Brabec P, Pavlovská L (Czech Republic)
Czech national registry of myotonic disorders
- 10.10 – 10.30 Vondráček Petr (Czech Republic)
Clinical trial of exon skipping on DMD
- 10.30 – 10.50 Petra Hedvičáková (Czech Republic)
Genetic trial - screening of DMD
- 10.50 – 11.10 *Coffee break*
- 11.10 – 11.30 Denis Duboc (France)
Current cardiac guidelines in NMD's
- 11.30 – 12.10 Juliet Rockett (Great Britain)
Dysphagia and Nutrition
- 12.10 – 12.30 Haberlová Jana (Czech Republic)
The Standards of Care for Muscular Dystrophies
- 12.30 – 12.50 Dobroslava Jandová (Czech Republic)
Rehabilitation limits for people with neuromuscular disorders
- 13.00 – 14.15 *Lunch*



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Afternoon session

Chairpersons: Zuzana Vojáčková, Tomislav Goll, Silvia Petruchová, Ivo Jakovljevič

14.30 – 14.50 David Kemlink (Czech Republic)

Noninvasive ventilatory support in persons with DMD

14.50 – 15.10 Denisa Raffajová (Slovakia)

Invasive ventilator support for persons with DMD

15.10 – 15.30 Arpád von Moers (Germany)

Neuromuscular centers in Germany

15.30 – 15.50 Anna Ambrosini (Italy)

**Bringing the voice of people with NMDs within the international NMD community.
What role of associations and charities?**

15.50 – 16.10 General discussions

16.10 – 16.30 *Coffee Break*

16.30 – 20.30 **41st Annual General Meeting** (delegates only)

20.30 – 22.00 *Dinner*

Saturday, September 10th, 2011

II. The social assessment of people with neuromuscular disorders

Chairpersons: Tadej Korosec, Marco Rasconi, Mária Duračinská, Tibor Köböl

7.30 – 8:45 *Breakfast*

9.00 – 9.15 Cira Solimene and Marco Rasconi (Italy)

Home sweet home: an associative experience of independent living

9.15 – 9.30 Gabriela Svičková (Slovakia)

Hyperprotection may be more restrictive than the disability itself.

9.30 – 9.45 Tibor Köböl (Slovakia)

Social aspects of disability

9.45 – 10.00 Kočová Helena (Czech Republic)

The support of families with SMA

10.00 – 10.15 Josef Zajíc (Czech Republic)

Presentation of CMT organization

10.15 – 10.30 Pavel Trojan (Czech Republic)

Presentation of Parent Project organization

10.30 – 11.00 Jitka Kačírková (Czech Republic)

Living with Muscular Dystrophy



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- 11.00 – 11.20 Polovina nebe - Ondřej Sedláček, Dita Horochovská, Daniela Rázková (Czech Republic)
PC voice control
- 11.20 – 11.45 *Coffee break*
- 11.45 – 12.00 Ivanka Jovanović (Serbia)
Legal framework for status of persons with neuromuscular disorders in Serbia
- 12.00 – 12.15 Mária Duračinská (Slovakia)
Persons with neuromuscular disability and the political document EDF regarding the chronic diseases
- 12.15 – 12.30 Jan Jakobsen (Denmark)
Hope for healing: the victims of speculation in genetic engineering
- 12.30 – 12.45 Tadej Korošec (Slovenia)
Restorative rehabilitation of people with NMD in Izola, Slovenia
- 12.45 – 13.00 General discussions
- 13.00 – 15.00 *Lunch*
- 15.00 – 19.30 *Sightseeing of Prague*
- 20.00 *Gala Dinner*

Sunday, September 11th, 2011

- 09.30 – 11.00 Executive Committee Meeting (members only)
Departure of Participants / Transport to airport