



eamda

42nd Annual General Meeting

Budapest, October 4-7, 2012



Danubius Health Spa Resort, Margaret island, Budapest, Hungary

Thursday, October 4th, 2012

- 'till 14.00 Arrival of Delegates / Transport from airport
 15.00 – 16.00 Registration
 16.00 – 18.00 Executive Committee Meeting (members only)
 19.00 – 21.00 *Dinner and informal gathering*

Friday, October 5th, 2012

Morning session

7.30 – 8:45 *Breakfast*

9.00 – 9.30 **Official opening and speeches**

President of EAMDA, Boris Sustarsic

President of MDA of Hungary, Dr. Thiesz Jozsef

Assistant secretary of State from the Ministry of Human Resources State Secretariat for Social, Family and youth affairs, Asztalosné Zupcsán Erika

Assistant mayor for health and social welfare in Budapest, Dr. Szentés Tamás

I. Medical perspectives for people with neuromuscular disorders

Chairperson: Dr. Agnes Herczegfalvi

- 9.30 – 10.00 Karcagi V., Garami M., Herczegfalvi Á.
Genetic diagnosis and patient registry of Hungarian DMD and SMA patients in collaboration with TREAT-NMD and CARE-NMD
- 10.00 – 10.30 Dr. Agnes Herczegfalvi, Neuromuscular Diseases Centre, TREAT-NMD
New perspectives for the Duchenne Muscular dystrophy patients - Care living in Hungary
- 10.30 – 11.00 *Prof.dr. Milan R. Dimitrijević, Houston, Vienna, Ljubljana*
Neuromuscular disorders and restorative neurology
- 11.00 – 11.30 *Coffee break*
- 11.30 – 12.00 Mija Meznaric, MD PhD, University of Ljubljana, Institute of Anatomy, Slovenia
Current challenges in the area of medical trials in NMD
- 12.00 – 12.30 Prof. Dr. Anton Zupan, University Rehabilitation Institute, Slovenia
Useful rehabilitation programs for people with NMD
a) Swimming and other forms of exercise in water for people with NMD
b) Assistive technology and methods of assistance for people with NMD
- 12.30 – 13.00 General Discussion
- 13.00 – 14.30 *Lunch*



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Afternoon session

16.00 – 18.00 **42nd Annual General Meeting** (delegates only)

19.00 *Dinner*

Saturday, October 6th, 2012

II. Disability aspects of people with neuromuscular disorders

Chairperson: Dr. Thiesz Jozsef

09.00 – 09.20 Erzsébet Földesi, Vice-President of EDF

The European Disability Forum and its possible collaboration with EAMDA

09.20 – 09.40 Dr. Thiesz Jozsef, President of MDA of Hungary

Social integration of people with NMD in Hungary

09.40 – 10.00 Andrea Lukacs, Gabriella Oberrecht

Development of the Hungarian DMD community – the role of the national POs

10.00 – 10.20 Ms. Fanni Hozleiter

Smile – life in wheelchair

10.20 – 10.40 Boris Sustarsic, President of EAMDA

Is the primary identity of people with neuromuscular disorders being disabled or being patients?

10.40 – 11.00 Marica Miric, MDA of Croatia

Support services for families of children with neuromuscular diseases

11.00 – 11.30 *Coffee break*

11.30 – 11.50 Dr. Miroslav Vrankic, Faculty of Engineering, University of Rijeka, Croatia

Andrej Jaksic, Bauerfeind d.o.o., Slovenia

Implementation of modern ICT to increase the quality of life of disabled people

11.50 – 12.30 General Discussion

12.30 – 15.00 Lunch and break

15.00 Sightseeing of Budapest

19.00 *Dinner on a Boat*



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Sunday, October 7th, 2012

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