

eamda

42nd Annual General Meeting





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. Szentes Tamás

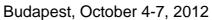
I. Medical perspectives for people with neuromuscular disorders

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 - 10.30Dr. 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	42 nd Annual General Meeting (delegates only)
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19.00 Dinner

Saturday, October 6th, 2012

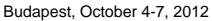
II. Disability aspects of people with neuromuscular disorders

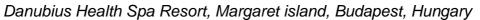
Chairperson:	Dr. Thiesz Jozsef
09.00 - 09.20	Erzsébet Földesi, Vice-President of EDF The European Disability Forum and its possible collaboration with EAMDA
09.20 - 09.40	Dr. Thiesz Jozsef, President of MDA of Hungary Social integration of people with NMD in Hungary
09.40 – 10.00	Andrea Lukacs, Gabriella 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 19.00	Sightseeing of Budapest 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