

Thursday 11th September 2008

Arrival of Delegates / Transport from airport

16.00 – 17.00 Registration

17.30 – 19.00 *Executive Committee Meeting*

19.00 – 21.00 Welcome party

Speeches by: President of EAMDA, Mr. Boris Šuštaršič

Chairperson of the Bulgarian MDA, Ms. Violetta Antonova

Friday 12th September 2008

EAMDA ANNUAL GENERAL MEETING and pre-conference workshops

07.30 – 08.45 Breakfast

38th Annual General Meeting EAMDA 2008

09.00 – 11.00 EAMDA Annual General Meeting – members only

11.00 – 11.30 Coffee Break

11.30 – 13:00 Pre-conference workshop part 1. - members only

The role of patient organisations in the roadmap to therapy and better standards of care. After a short introduction by Peter Streng the participants will reflect on the past year and the actions undertaken. (See report 2007-attachment)

13.00 – 14.30 LUNCH

14.30 – 16.30 Pre-conference workshop part 2. - members only

Access to social and health care an introduction to the European situation.

Daily life: housing, work, school, freetime. Three young people with a Neuro-Muscular Disease: Hann van Schendel (The Netherlands), Ivo Jakovljevic (Slovenia) and Tibor Kobol (Slovakia), will give a presentation about their daily life, their experiences. After their presentations we will discuss and talk about the presentations. What do you take home from these presentations and which actions can be undertaken in your country?



Hann van Schendel



Maria Duracinska



Ivo Jakovljevic



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38th Annual General Meeting
September 11 - 14, 2008, Sofia, BULGARIA



17.30 - Sightseeing in Sofia including a visit to the Alexander Nevski Cathedral
Dinner in Sofia

Saturday 13th September 2008

EAMDA ANNUAL CONFERENCE

09.00 – 09.30 **Official Opening /welcome speeches**
- President of EAMDA, Mr. Boris Šuštaršič
- Chairperson of the Bulgarian MDA, Ms. Violetta Antonova
- Representatives of Health ministry / Authorities

Opening address made by:

Mrs. Zorka Parvanova, Ph.D., first lady of Bulgaria

09.30 -11.00 **Session 1: Research & Therapy Development Proces**

Neuromuscular diseases in Bulgaria

Prof. Dr Ivo Kremensky - National Genetics Laboratory, Molecular Medicine Center, Sofia Medical University, Sofia, Bulgaria.

The importance of the concept of rare diseases for NMD

Assoc. Prof. Dr Ivan Ivanov, University Hospital Plovdiv

Information Centre for Rare Diseases and Orphan Drugs (ICRDOD).

The role of patient organisations in research, therapy development and disease management

Drs Peter Streng., ENMC, The Netherlands or Dr Marita Pohlschmidt, Muscular Dystrophy Campaign MDC, United Kingdom.

TREAT-NMD – an overview, networking in NMD investigation and treatment, Eastern European perspectives

Dr Stephen Lynn, TREAT-NMD project manager, University of Newcastle.

Registries and Biobanks – aims and practical implications

Dr Luisa Politano, University of Naples, Eurobiobank Italy.

Registries – the Bulgarian experience, the Bulgarian NMD project (Ministry of Education and Science), TREAT NMD support,

Prof. Dr Ivailo Tournev, Clinic of Neurology, University Hospital Alexandrovska; Bulgarian NMD Society.

Questions & Answers by speakers and audience

11.00 – 11.25 Coffee break



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11.30 – 13.00 Session 2: *Treatment and Treatment Opportunities*

"A treatment for Pompe's disease: The road to access"

Dr Hans Schikan, director Genzyme Europe BV, The Netherlands.

"Reference Center from concept to reality"

Dr Hervé Laouenan, Association Française contre les Myopathies AFM, France.

"Developments in research and future treatment opportunities in CMT (HMSN)"

Prof. Dr P. De Jonghe, Dept. Biomedical sciences, University of Antwerp, Belgium.

"Future treatment opportunities in DMD/BMD clinical trials, phases in clinical trials, inclusion criteria, obstacles to inclusions"

Dr Veronique Humbertclaude, University Hospital of Montpellier, France.

Questions & Answers by speakers and audience

13.00 – 13.55 LUNCH

14.00 – 15.30 Session 3: *Standards of Care and Practical Issues*

"Standards of care, international experts consensus – SMA - available and DMD – in preparation, an overview"

Dr Thomas Sejersen, Karolinska Institute, Sweden.

"Standards of care for people with NMD – current situation in BG, ways to improve"

Dr Velina Guerguelcheva, Sofia Medical University and Assoc. Prof. Dr Veneta Bojinova, Clinic of Child Neurology, Specialized Hospital in Neurology and Psychiatry "St. Naum".

"Technical aids and technology for people with NMD", existing and new technologies

Prof Dr A. Zupan, Institute for Rehabilitation of the Republic of Slovenia

"Fysiotherapy and rehabilitation in daily disease management"

Dr Birgit Steffensen, Muskelsvindfonden, Denmark

15.30 – 16.00 Coffee break

16.00 – 17.00 General Discussion with a forum of all speakers

17.00 - 17.15 Wrap up and conclusions by EAMDA
Official Closing by the President of EAMDA

17.30 – 19.00 TREAT NMD network meeting for interested physicians and researchers

20.00 DINNER for Speakers, Bulgarian neurologists and EAMDA delegates