

**Under the auspices of the President of Serbia  
Boris Tadić**

**Thursday, September 17<sup>th</sup>, 2009**

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 Sustarsic  
- Members of Muscular Dystrophy Association of Serbia (MDAS):  
Ms. Ivanka Jovanovic, Ms. Gordana Rajkov, Mr. Radovan Pavlovic

21.00 – 22.00 **Dinner**

**Friday, September 18<sup>th</sup>, 2009**

09.00 – 10.00

**Official Opening / welcome speeches**

- President of EAMDA, Mr. Boris Sustarsic
- Chairperson of the Serbian MDA, Ms. Ivanka Jovanovic
- The Minister of Health of the Republic of Serbia, Prof. Tomica Milosavljevic, MD. PhD
- Other officials

**Artistic program**

**EAMDA Annual Scientific Conference**

***Session I: The molecular and genetic basis of neuromuscular diseases***

**Chairperson: Slobodanka Todorović, Belgrade, Serbia**

- 10.00 – 10.20 General concepts of mechanisms of hereditary diseases:  
Neuromuscular disorders in focus  
*Stanka Romac, Professor of molecular biology, Biological Faculty, University of Belgrade, Serbia*
- 10.20 – 10.40 The molecular and genetic basis of muscular dystrophies  
*Slobodanka Todorović, Professor of Neurology, Medical Faculty, University of Belgrade, Clinic for Neurology and Psychiatry for Children and Youth, Serbia*
- 10.40 – 11.00 The molecular and genetic basis of neuropathies  
*Vedrana Milić-Rašić, Associate Professor of Neurology, Medical Faculty, University of Belgrade, Clinic for Neurology and Psychiatry for Children and Youth, Serbia*
- 11.00 – 11.20 Comprehensive clinical investigations in neuromuscular diseases  
*Zoran Mitrović, Reference Center for Neuromuscular Diseases, ClinicalCenter, Zagreb, Croatia*
- 11.20 – 11.40 Discussion
- 11.40 – 12.00 **Coffee break**

***Session II: Ongoing research and clinical trials***

**Chairperson: Thomas Sejersen, Stockholm, Sweden**

- 12.00 – 12.20 Innovative research and clinical trials on DMD and SMA  
*Thomas Sejersen, Associate Professor of Neurology, Karolinska University Hospital, Stockholm, Sweden*
- 12.20 – 12.40 The TREAT-NMD network: bringing down the barriers in translational research for neuromuscular diseases.  
*Anna Ambrosini, Research Program Manager, Telethon Milan, Italy*
- 12.40 – 13.00 AFM scientific strategies: not all eggs in the same basket  
*Hervé Laouenan, European Project Manager, AFM-Scientific Affairs, France*
- 12.40 – 13.00 Neurocontrol of the locomotion in progressive neuromuscular diseases  
*Aleš Pražnikar, MD, PhD, neurologist, Slovenia*
- 13.00 – 13.20 Discussion
- 13.20 – 15.00 **Lunch**

**Session III: Treatment of neuromuscular disorders: 2009.**

**Chairperson:**

- 15.00 – 15.20 Treatment of Neuromuscular disorders: psychiatric and medicamentose approach  
*Janez Zidar, Professor of Neurology, University of Ljubljana, University Medical Centre Ljubljana, Institute of Clinical Neurophysiology, Slovenia*
- 15.20 – 15.40 Home mechanical ventilation in neuromuscular patients  
*Miodrag Vukčević, Associate Professor, Institute for Pulmonary Diseases, Medical Faculty, University of Belgrade, Serbia*
- 15.40 – 16.00 Orthopaedic treatment of spinal deformities in neuromuscular patients  
*Zdeslav Milinković, Professor of Orthopaedic Surgery, University of Belgrade, Institute for orthopaedic and surgical diseases „Banjica“, Serbia*
- 16.00 – 16.20 **Coffee break**
- 16.20 – 16.40 Immune mediated deterioration of inherited neuromuscular diseases and treatment.  
*Slobodan Apostolski, MD, PhD, Neurological Clinic "Apostolski", Belgrade, Serbia*
- 16.40 – 17.00 Waiting for the title  
*Ksenija Gorni, MD, Centro Clinico NEMO, Milano, Italy*
- 17.00 – 17.20 Discussion
- 17.20 – 17.40 **Coffee break**

**Session IV: Ethical and Psychological challenges**

**Chairperson: John Marquardt, Denmark**

- 17.40 – 18.00 Emerging Issues in Ethics for Neuromuscular Disorders  
*Dr Pauline McCormack, Research Associate Policy, Ethics and Life Sciences/TREAT-NMD Newcastle University, UK*
- 18.00 – 18.20 Rehabilitation of families with neuromuscular diseases  
*John Marquardt, MSc Psychology, Rehabiliterings Centre for Neuromuscular Diseases (RCfM), Denmark*
- 18.20 – 18.40 Discussion
- 20.00 – 23.00 **Dinner for Speakers, doctors and EAMDA delegates**
- 21.00 Inauguration of Annual Distinguished Lecture  
Brain and Neuromuscular Disorders  
Prof. Dr Milan R. Dimitrijević, Ljubljana, Houston, Vienna**

**Saturday, September 19<sup>th</sup>, 2009**

07.30 – 09.00 **Breakfast**

Session: Independent living of persons with neuromuscular diseases – experience and practices in the Region and EU

***PART I – Experiences in Serbia***

09.00 – 09.15 Introduction speech – Boris Sustarsic, Ivanka Jovanovic

09.15 – 09.30 Welcome speech – Rasim Ljajic, Minister of labour and social policy of the Government of the Republic of Serbia

09.30 – 09.50 Presentation of the results to date in the implementation of the PA Service Programme in Serbia  
- Gordana Rajkov, International coordinator in the Centre for independent living of persons with disabilities, Serbia, and the manager of the SPAS project

09.50 – 10.10 Opportunities for future developments of the PA Service in Serbia from the perspective of drafting the new Law on social protection  
- Ljiljana Lucic, State Secretary in the Ministry of labour and social policy of the Republic of Serbia

10.10 – 10.30 Discussion

10.30 – 11.00 **Coffee break**

***PART II – Experiences in the Region and EU (11.00 – 13.00)***

11.00 – 11.15 Experiences and examples of good practice: Croatia

11.15 – 11.30 Experiences and examples of good practice: Slovenia

11.30 – 11.45 Experiences and examples of good practice: Italy

12.00 – 12.15 Experiences and examples of good practice: Denmark

12.15 – 12.30 Experiences and examples of good practice: France

12.30 – 12.45 Experiences and examples of good practice: Slovakia

12.45 – 13.15 Plenary discussion and conclusions

13.15 – 14.20 **Lunch**



**eamda**

39<sup>th</sup> Annual General Meeting

September 17 - 20, 2009, Beograd, SERBIA



Muscular Dystrophy  
Association of Serbia



14.20 – 16.20 *39<sup>th</sup> Annual Executive Committee Meeting* (members only)

16.30 Sightseeing of Belgrade

**Dinner at the National restaurant**

**Sunday, September 20<sup>th</sup>, 2009**

### **EAMDA Closing Meeting**

07.00 – 09.00 **Breakfast**

09.30 – 11.00 Executive Committee Meeting

Departure of Participants/Transport to airport