



# 45<sup>th</sup> ANNUAL GENERAL MEETING

Belgrade, September 24-27, 2015  
Hotel Holliday Inn, Belgrade, Serbia



MUSCULAR  
DYSTROPHY  
ASSOCIATION  
OF SERBIA

## Medical, social and administrative part of the conference:

Hotel Holliday Inn, Belgrade, Serbia

### Thursday, September 24<sup>th</sup>, 2015 (Hotel Holliday Inn, Belgrade, Serbia)

**Until 12.00** Arrival of Delegates / Transport from airport  
**15.00 – 17.00** 1<sup>st</sup> Executive Committee Meeting (members only)  
**17.00 – 19.00** Informal individual meetings  
**19.00 – 21.00** Dinner

### Friday, September 25<sup>th</sup>, 2015 (Hotel Holliday Inn, Belgrade, Serbia)

**09.00 – 09.30 Official opening and speeches**  
Minister of Labour, Employment and Social Affairs, Aleksandar Vulin  
Minister of Health, dr. Zoran Loncar  
Boris Sustarsic, President of EAMDA  
Ms. Ivanka Jovanovic, Vice-president of EAMDA and Mr. Predrag Bakic, President of Dystrophy Association of Serbia

## A) MEDICAL PART OF THE CONFERENCE

### I. Diagnostics and assessment of NMD

***“There are more disorders and conditions than we are discussing here.”***

**Chairperson:** prof.dr. Vedrana Milic Rasic, dr. Dragica Radojkovic

**09.30 – 09.45 [med 1] NMD SerbNet, Serbian Neuromuscular Disease Network**  
dr. Dragica Radojkovic, Institute of Molecular Genetics and Genetic Engineering, University of Belgrade

**09.45 – 10.00 [med 2] Diagnosis and symptomatic therapy of myotonic, limb girdle and other dystrophies**  
prof. dr. Vidosava Rakocevic Stojanovic and Stojan Peric, Neurology Clinic, Clinical Center of Serbia, School of Medicine, University of Belgrade

**10.00 – 10.15 [med 3] Diagnosis and symptomatic therapy of Duchene muscular dystrophy, spinal muscular atrophy, congenital myasthenic syndrome and inherited neuropathies**  
prof. dr. Vedrana Milic Rasic and dr. Ana Kosac, Clinic for Neurology and Psychiatry for Children and Youth, School of Medicine, University of Belgrade

**10.15 – 10.30 [med 4] Serbian registers and biobank**  
dr. Stojan Peric, Neurology Clinic, Clinical Center of Serbia, School of Medicine, University of Belgrade and dr. Dragica Radojkovic, Institute of Molecular Genetics and Genetic Engineering, University of Belgrade

**10.30 – 11.00 Coffee break**

**11.00 – 11.15 [med 5] Genetics in diagnostics of NMD**  
Milos Brkusanin, Center for Human Molecular Genetics, Faculty of Biology, University of Belgrade

**11.15 – 11.30 [med 6] Potential of genetically designed therapies for neuromuscular disorders**  
prof. dr. Dusanka Savic Pavicevic, Center for Human Molecular Genetics, Faculty of Biology, University of Belgrade

**11.30 – 11.45 [med 7] An overview of the medical image processing tools for the muscle tissue diagnosis assessment in MRI images**  
assist. dr. Olga Chambers, University of Ljubljana, Faculty of Electrical Engineering

**11.45 – 12.00 [med 8] Pompe disease: diagnosis and enzyme replacement therapy**  
prim. dr. Davorka Vranjes, University Hospital Centre Zagreb - Rebro  
prof. dr. sc. Ervina Bilic, University Hospital Centre Zagreb – Rebro

**12.00 – 12.30** Plenary debate

**12.30 – 14.30** Lunch break

***“Do they have some common underline mechanisms?”***

***II. Maintenance of altered capabilities, restorative rehabilitation and treatment***

***“Let us make friends from our opponents.”***

**Chairperson:** prof. dr. Osman Sinanovic, prof. dr. Milan R. Dimitrijevic, prof.dr. Janez Zidar

**14.30 – 14.45** [med 9] Introduction to Biogen’s NURTURE clinical study od ISIS-SMNRx in presymptomatic newborn

dr. Ksenija Gorni, Clinical center NEMO, Milano, Italy

**14.45 – 15.00** [med 10] Amyotrophic lateral sclerosis and respiratory problems - what can we do?

assist. prof. Blaz Koritnik, Institute of Clinical Neurophysiology, University Medical Centre Ljubljana

**15.00 – 15.15** [med 11] ALS treatment

prof. dr. Janez Zidar, Institute of Clinical Neurophysiology, University Medical Centre Ljubljana

**15.15 – 15.30** [med 12] (Haematopoietic) Stem cells therapy – possibilities and illusion

prof. dr. Dragana Vujic, Mother and Child Health Care Institute of Serbia

**15.30 – 16.00** Coffee break

**16.00 – 16.15** [med 13] Critical appraisal of outcome measures in neuromuscular disorders

assist. mag. Ales Praznikar, dr. med., University Medical Centre Ljubljana, Division of Neurology

**16.15 – 16.30** [med 14] Is physical exercise beneficial or maleficial for patients with neuromuscular disorders

assist. mag. Ales Praznikar, dr. med., University Medical Centre Ljubljana, Division of Neurology

**16.30 – 16.45** [med 15] Myasthenia gravis: diagnosis and therapy

prof. dr. Osman Sinanovic, Department of Neurology, University Clinical Center Tuzla

**16.45 – 17.00** [med 16] Spinal muscular atrophies: clinical and genetic heterogeneity

Anna Kostera-Pruszczyk, MD PhD, Department of Neurology, Medical University of Warsaw, Poland

**17.00 – 17.15** [med 17] Clinical aspects of myotonic dystrophy type 2

Rujana Sprljan Alfirov, dr.med., Department of Neurology, University Hospital Center Zagreb

**17.15 – 17.45** Plenary debate

***“Several components are contributors of integrals of neuromuscular disorders.”***

***“Muscle is generator of force and source of proprioception of nervous system.”***

### **III. Assistive technology and NMD**

***“Advanced technology can contribute to richness or poverty.”***

<b>Chairperson:</b>	<b>prof. dr. Anton Zupan</b>
<b>17.45 – 18.00</b>	<b>[med 18] Home ventilation and assisted cough</b> ass. prof. Miodrag Vukcevic, KBC Zemun, Medical School of Belgrade, Serbia
<b>18.00 – 18.15</b>	<b>[med 19] Assistive technology for a quality life of people with NMD</b> prof. dr. Anton Zupan, University Rehabilitation Institute, Republic of Slovenia
<b>18.15 – 18.30</b>	<b>[med 20] Assistive technology in physical therapy of NMD people</b> Alesa Kloosterwaard, Rehabilitation Center Dom dva topola, Izola (Slovenia)
<b>18.30 – 18.45</b>	<b>[med 21] Assistive technology for multimedia and alternative communication of NMD people</b> assist. dr. Mojca Debeljak, University Rehabilitation Institute, Republic of Slovenia
<b>18.45 – 19.00</b>	<b>[med 22] Robotics for better life of humans with disability</b> Dejan B. Popovic, PdD, Dr.Tech, Professor of Biomedical Engineering, University of Belgrade and member of Serbian Academy of Sciences and Arts, Belgrade, Serbia
<b>19.00 – 19.30</b>	<b>Plenary debate</b>
<b>19.30</b>	<b>Dinner</b>

***“Technological contribution to muscular dystrophy can support missing movements but let us try to add also connections with underline mechanisms.”***

**Saturday, September 26<sup>th</sup>, 2015 (Hotel Holliday Inn, Belgrade, Serbia)**

#### **B) SOCIAL PART OF THE CONFERENCE**

**09.00 – 11.00 45<sup>th</sup> Annual General Meeting**

*(Representatives of member associations only)*

Agenda is going to be presented on the conference

***Independent living for people with NMD – experiences and practices in the Region and EU***

***“The disability can be a new ability.”***

**Chairperson: Gordana Rajkov, President of Center for independent living of Serbia**

#### **PART I – Experiences in Serbia**

**11.00 – 11.15 Opportunities for future developments of the PA Service in Belgrade**

Natasa Stanisavljevic, Head of the Secretariat for Social Care of Belgrade

**11.15 – 11.30 Presentation of the results to date in the implementation of the PA Service programme in Serbia**

Gordana Rajkov, President of Centre for independent living of persons with disabilities

**11.30 – 11.45 Discussion**

#### **PART II – Experiences in the Region and EU**

**11.45 – 12.00 Experiences and examples of good practice: Croatia**

**12.00 – 12.15 Experiences and examples of good practice: Slovenia**

**12.15 – 12.30 Experiences and examples of good practice: Czech Republic**

**12.30 – 12.45 Experiences and examples of good practice: Bulgaria**

**12.45 – 13.05 Discussion**

**13.05 – 13.30 Independent living in literature and movies**

Jelena Milosevic, philologist/communicator, MDA of Serbia



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<b>13.30 – 15.00</b>	<b>Lunch</b>
<b>15.30 – 19.30</b>	<b>Sightseeing of Belgrade</b>
<b>19.30 – 23.00</b>	<b>Dinner at the Restaurant “Caruso”</b>

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**Sunday, September 27<sup>th</sup>, 2015**

09.00 – 10.30 2<sup>nd</sup> Executive Committee Meeting (EC members only)  
Departure of Participants / Transport to airport

**FRIENDS OF THE CONFERENCE**



**genzyme**  
A SANOFI COMPANY



**Republic of Serbia: Ministry of  
Labour, Employment, Veteran  
and Social Affairs**