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DISORDERS ASSOCIATIONS

SOCIAL AND BIOLOGICAL PERSPECTIVES OF PERSONS WITH NEUROMUSCULAR DISORDERS

Boris Šuštaršič, EAMDA President

40th EAMDA AGM, Milano 16.-19.9.2010



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SOCIAL AND BIOLOGICAL PERSPECTIVES OF PERSONS WITH NEUROMUSCULAR DISORDERS

Introduction

I. Social perspectives

II. Biological perspectives

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Introduction

1. The social fate of persons with neuromuscular disorders (NMD) through various periods and social environments differed dramatically.

2. The social fate did not progress continually.



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Introduction

3. Enormous increase of knowledge on NMD by Physicians and Social environment.

4. But still –NIHILISTIC PERCEPTION ON PERSONS WITH NMD.



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Introduction

3. Enormous increase of knowledge on NMD by Physicians and Social environment.

4. But still –NIHILISTIC PERCEPTION ON PERSONS WITH NMD. Like short life expectancy, not reasonable for financial investments



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Introduction

5. During last 50 years that nihilism was largely suppressed, due to implementation of human and social rights of persons with disabilities



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6. Each financial and economic crisis resurrects this nihilism.

Answer:

**EACH PERSONS WITH NMD AND THEIR
FAMILIES HAVE TO THINK ACTIVELY
ABOUT THEIR FUTURE**

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I. Social perspectives

Reasons for individual NMD differ.

INDEPENDENT LIVING.

Most persons with NMD sooner or later become more or less dependant on the physical assistance from other persons.



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I. Social perspectives

Cruel fact: SHORT or REDUCED life expectancy of Persons with NMD.

But PROLONGED due to:

- developments in internal medicine
- medical interventions
- quality nutrition
- technical appliances
- assistive technology

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I. Social perspectives

NOT ETHICAL to leave persons with NMD in a passive social life.

Therefore Persons with NMD should be encouraged to live and active social life, own social decisions.



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I. Social perspectives

**40th AGM – DEFINING TO
SOCIAL IDENTITY OF PERSONS
WITH NMD AS DISABLED
CITIZENS**

**Chronic patients have no real
social perspective in EU. WHY?**

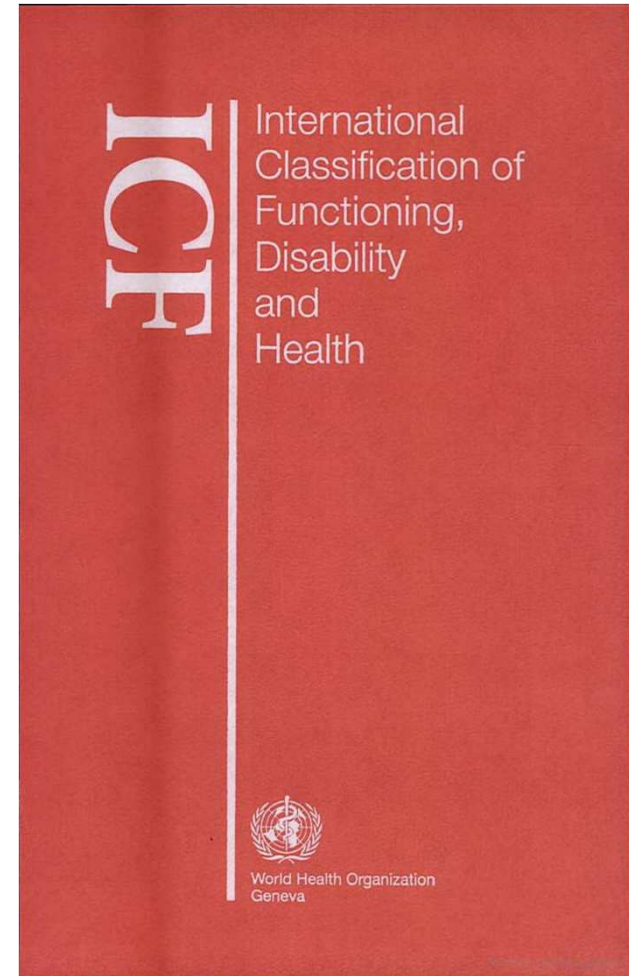
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I. Social perspectives

1. International classification of Functioning, Disability and Health. (WHO, 2001) - ICF



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I. Social perspectives

2. Convention on the rights of Persons with Disabilities. (UN, 2006) - CRPD

Convention on
the Rights of Persons
with Disabilities and
Optional Protocol



UNITED NATIONS

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I. Social perspectives

1. ICF

- complementary biological and social model of disability

2. CRPD

- specific measures by states for severe disabled persons



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I. Social perspectives

Most desired life-style of persons
with NMD

unlimited integration and
inclusion.



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I. Social perspectives

Due to progressive disability and the fact of severe impairments

specially accommodated institutions where persons with NMD can live and work are necessary.

BUT



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I. Social perspectives

To be absolutely CLEAR:

Institutions must be:

- fully open
- participation of persons with NMD in the management and realisation of special forms of independent living.



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I. Social perspectives

Last 40 years Slovenian persons with NMD established and developed 3 institutions.

Muscular Dystrophy Association of Slovenia

www.drustvo-distrofikov.si



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Muscular Dystrophy Association of Slovenia was established in 1970 in Ljubljana. At the beginning it was a part of Udruženje Distrofikar Jugoslavije (Muscular Dystrophy Federation of Yugoslavia) which was one of the founders of EAMDA.



It was a happy coincidence that in 1970 the Republic of Slovenia was amending the Health Care Act. We eventually succeeded in classifying the muscular and neuromuscular diseases into the compulsory scope of health insurance which encompasses diagnosis, medical treatment, rehabilitation and provision of medical aids. On that legal basis a special Centre for neuromuscular disorders was established by the Institute of Clinical Neurophysiology at the University Medical Centre in Ljubljana. Among other the Centre keeps the national register of people with neuromuscular disorders and employs also a social worker.



If the field of health care were not regulated properly the Association would have to deal with the social identity of the patients. Fortunately, we have been able to focus our activities on the quality of life and social identity of disabled citizens. The persons performing the leading functions in the Association all have neuromuscular disorders, which reflects the content of our guidelines.



In the framework of the first social programme the Association purchased a van and employed a driver. During the three decades we have developed a mobile and assistance service operating with 12 adapted vehicles and employing 10 drivers and 36 personal assistants who enable the disabled persons to lead an active life.



The Association encourages and implements the programmes aimed at preserving health, education, occupational training and employment, housing, provision of medical and technical aids, informing, leisure activities and other.



In co-operation with other Slovenian disabled people's organisations the Association contributed to the regulation of basic financing through the public foundation of lottery funds which is complemented by project financing from various sources. The Association is also an active member of the National Council of Disabled People's Organisations of Slovenia (NSIOS).



The Republic of Slovenia is a Central European country with a surface area of 20,273 km and a population of two million inhabitants.



Ljubljana is the Capital city of Slovenia and has a central geographical position in the country.

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BIROGRAFIKABORI D.O.O.

www.birografikabori.si



Regular employment is hardly ever attainable for people with neuromuscular disorders who inevitably depend for 24 hours a day on some kind of physical assistance of other people and are usually forced to use a wheelchair. This was the main reason why the Muscular Dystrophy Association of Slovenia started to develop the experimental economic activity of selling photocopying services already back in 1977. In February 1980 it established a company for occupational training and employment and named it Birografika BORI.



Birografika BORI has developed into one of the leading companies on the Slovenian market offering quality graphic services under competitive market conditions. The company prides itself on the modern internal information system enabling efficient operations and state-of-the-art machinery based on the latest technological developments in the EU.



The company is 100% owned by the Muscular Dystrophy Association of Slovenia and has the status of a company employing disabled people due to which it is entitled to certain economic relief related to expenditure in order to compensate for the lower productivity levels of individual people with neuromuscular disorders and additional social activities related to the disability.



Currently Birografika BORI employs 94 persons of which 47 are disabled. Since its establishment the share of disabled people among the total employees has constantly been equal to or above 50%. Most leading positions are carried out by the people with neuromuscular disorders who, together with the highly qualified experts, operate the company in accordance with the professional, business and social ethics.

The goal of Birografika BORI was not to employ all people with neuromuscular disorders in Slovenia but to demonstrate on a practical basis that those people can also be employed and help achieve high productivity although their disability requires specific technological, economic and social solutions. An important factor of this success story was that the Muscular Dystrophy Association of Slovenia has a guaranteed lasting autonomous financing position although there has been no need until now to finance the activities of the Association from the income of Birografika BORI.



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DOM DVA TOPOLA D.O.O.

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DOM DVA TOPOLA
HOME TWO POPLARS

Having achieved successful medical treatment of people with neuromuscular disorders in health establishments, the Muscular Dystrophy Association of Slovenia has also examined a possibility of providing out-hospital medical rehabilitation since it encompasses some important social elements which help the disabled form a positive attitude towards their body and towards the social environment. Moreover, the disabled and their parents have an opportunity to learn how to take care of their health in a domestic environment and to exchange life experience in overcoming certain difficulties. Thus in 1985 the Association purchased the premises of an abandoned hospital with a park situated on the coast in the town of Topola.



However, the premises were not adapted for people in wheelchairs, the installation was disused and the equipment decrepit. It was difficult enough for the Association to raise the funds to purchase the premises so it ran out of the money for a thorough renovation and the purchase of modern equipment. We therefore drew up a long-term plan of gradual modernisation in accordance with the modest annual funding we receive. Although the modernisation has not been finished we have achieved the capacity of 185 beds. Nevertheless, the above problems do not prevent the realisation of the medically justified restorative rehabilitation of groups of disabled people every summer led by the Institute for Rehabilitation of the Republic of Slovenia. The physiotherapy and hydrotherapy are carried out by the physiotherapists and other personnel of the Home Two Poplars in organisational co-operation with the Muscular Dystrophy Association of Slovenia which is the founder and 100% owner of the Home.



Through the Association the Home every year receives the funds from the Health Insurance for the restorative rehabilitation of 400 people with neuromuscular disorders and 150 personal assistants, while the extended and complementary rehabilitation programmes are financed directly from the funds of the Association and by the users themselves. During the out-of-season periods the Association carries out numerous social programmes (supplementary training, temporary residence, recreation).



In 1988 the Muscular Dystrophy Association of Slovenia in co-operation with the Association of the Blind and Partially-Sighted of Slovenia obtained the space for the construction of a joint adapted beach which was architecturally designed so that one half is intended for the people with neuromuscular disorders and the other half for the blind and partially-sighted.



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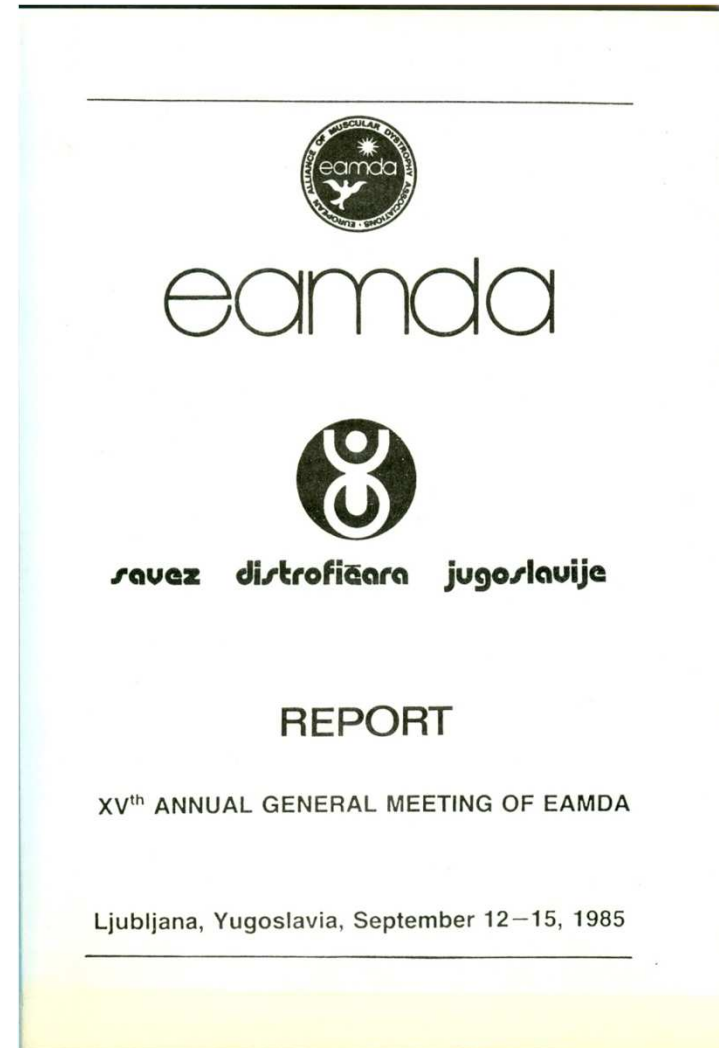
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I. Social perspectives

A report about those
was held at the 15th
EAMDA AGM,
september 1985 in
Ljubljana



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At the 32nd EAMDA
AGM with the title
“Symposium on
biological and social
resources for
advancement of the
quality of life of people
with NMD, Ljubljana
september 2004

Zdravniški vestnik
JOURNAL OF SLOVENE MEDICAL ASSOCIATION, LJUBLJANA, YEAR 73, JUNE 2004, Page II-1-160, SUPPL. II

SYMPOSIUM ON BIOLOGICAL AND SOCIAL RESOURCES FOR THE ADVANCEMENT OF THE QUALITY OF LIFE OF PEOPLE WITH NEUROMUSCULAR DISORDERS

LEADING ARTICLE

With future in mind, A. Pražnikar, M. R. Dimitrijević 1

ARTICLES

Biology of some neuromuscular disorders, G. Vrbova, I. Hausmanowa-Petrusewicz 3

Remarks on neurocontrol of the hand and significance of afferent input, N. Sarabon, M. M. Dimitrijević, J. Zidar, M. R. Dimitrijević 11

Upper limb functional assessment using haptic interface, A. Bardorfer, M. Munih, A. Zupan, B. Ceru 19

Neurophysiological basis of functional de-afferentation of the nervous system caused by weak or absent muscle contractions, N. Sarabon, M. R. Dimitrijević 25

First sound evidence of muscle regeneration in recovery of function of human permanent denervated muscle by a long-lasting FES training: Biopsy findings, H. Kern, C. Hofer, M. Moedlin, C. Forstner, M. Vogelauer, W. Richter, W. Mayr, M. E. Zanin, K. Rossini, U. Carraro 29

Assessment of grip force control in patients with muscular dystrophy, G. Kurillo, T. Bajd, A. Zupan 33

Functional magnetic resonance imaging of brain motor areas in hereditary spastic paraparesis patients, B. Koritnik, J. Knific, J. Zidar 39

Robotic application in people with weak muscles – Standing and walking, Z. Matjačić 43

Rehabilitation programs for people with neuromuscular disorders, A. Zupan 47

Functions of a neuromuscular centre, J. Zidar 51

Proposal of a ad hoc committee of EAMDA on possible improvement of clinical practice, A. Pražnikar, M. Šostarko, A. Zupan, M. Mežnarič-Petruša, M. R. Dimitrijević, G. Vrbova 55

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I. Social perspectives

All three institutions are equipped with modern technology.

They function efficiently.

Their future is sufficiently ensured.



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I. Social perspectives

Our graphic company carried out a high technical quality printing of two representative books:

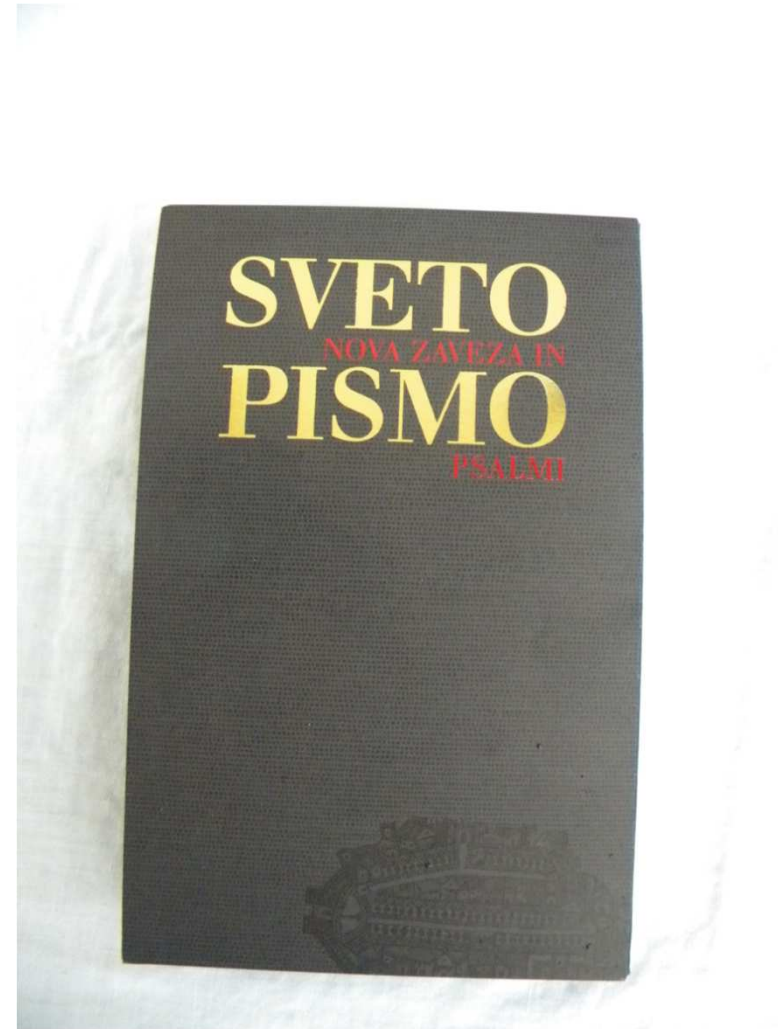
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I. Social perspectives

The new translation
of the Jerusalem
Bible in Slovene
language



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**I. Social
perspectives**
The history of
British Royal guards
on the occasion of
their 500th
anniversary

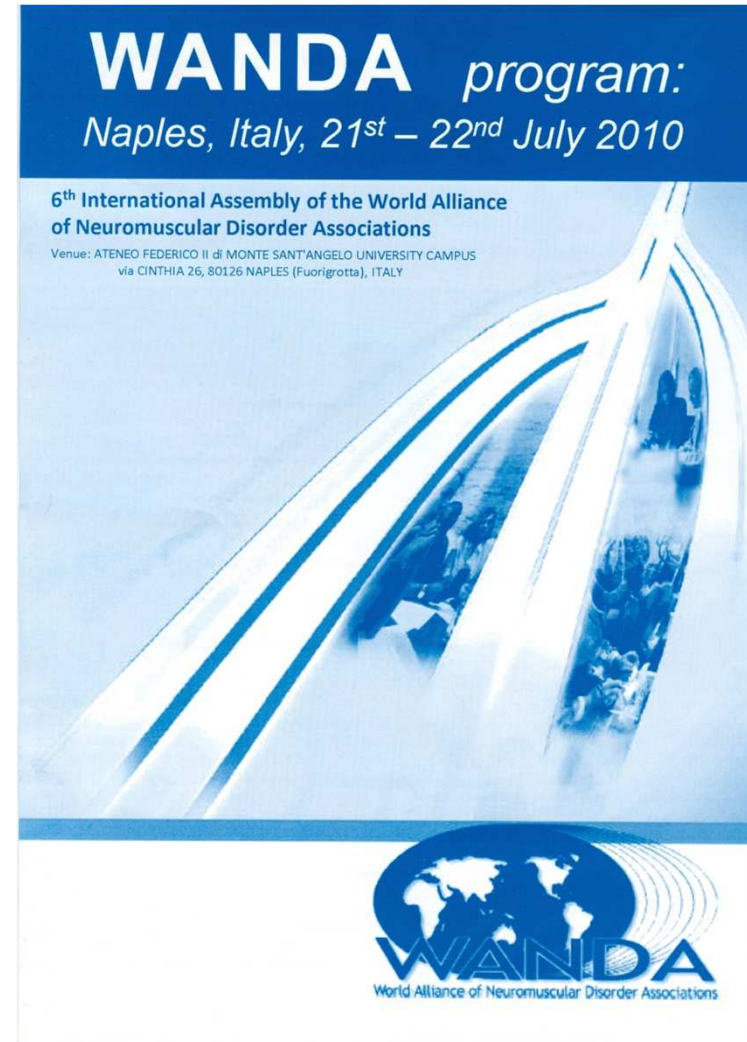


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**I. Biological
perspectives
OUTCOMES of the
6th WANDA
Assembly, July
2010 Neaple
within the 12th
ICNMD**



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I. Biological perspectives

1. No treatment can be expected in the near future.

2. Persons with NMD may still expect only biological potentials that they have in view of the already quite foreseeable course of individual diseases.



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I. Biological perspectives

TREAT – NMD efficiently integrates existing knowledge, basic scientific researches, clinical work of physicians.

BUT

insufficient attention to development of restorative neurology for progressive
NMD



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I. Biological perspectives

Important for EAMDA:

Clear position there are scientific findings on the benefits of clinical medical treatment which can in certain segments undoubtedly contribute to the preservation or modification of biological potentials of persons with NMD.



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I. Biological perspectives

Lecture by dr. Milan R. Dimitrijevič entitled “**Brain and Neuromuscular Disorders**” which he delivered at the 39th EAMDA AGM in Belgrade last year, laying special stress on the motor control and its social implication

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39th Annual General Meeting 17th to 20th September 2009 in Belgrade, Serbia

Brain and Neuromuscular Disorders

Motor Control and its Social Implication

Milan R Dimitrijevic

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I. Biological perspectives

Persons with NMD and their wider social environment unaware of the fact that persons with NMS have a 20% higher intelligence.

A biological and social advantage!



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I. Biological perspectives

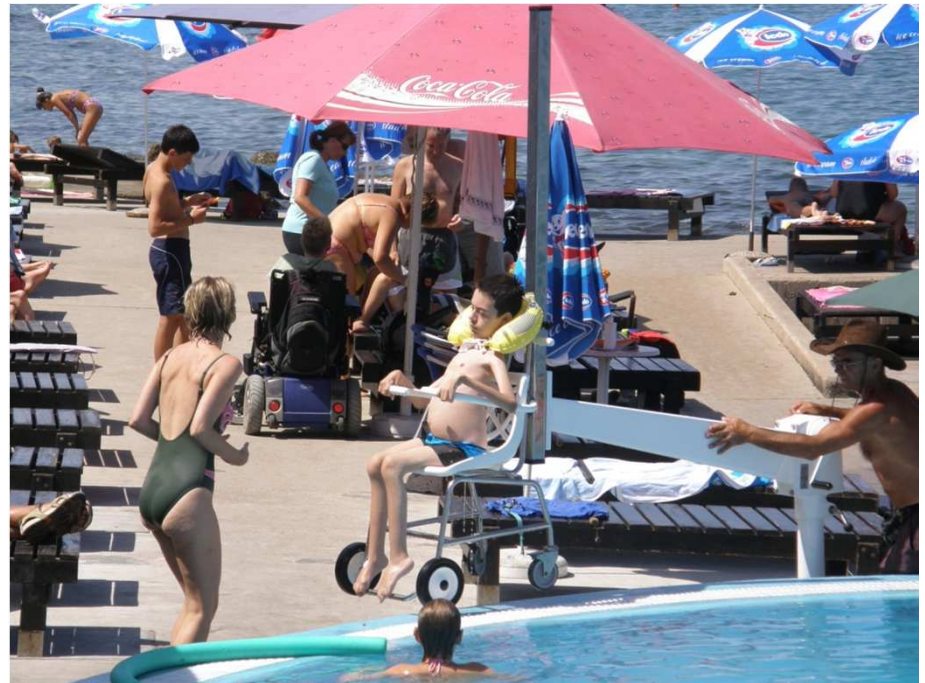
Muscular Association of Slovenia putted always big efforts into preservation of health of persons with NMD.

Purchase of abandoned hospital in 1985 – today Dom dva topola – execution of restorative rehabilitation programmes and other complementary social programmes.

Muscular dystrophy Association of Slovenia is 100% owner of the premises Dom dva topola



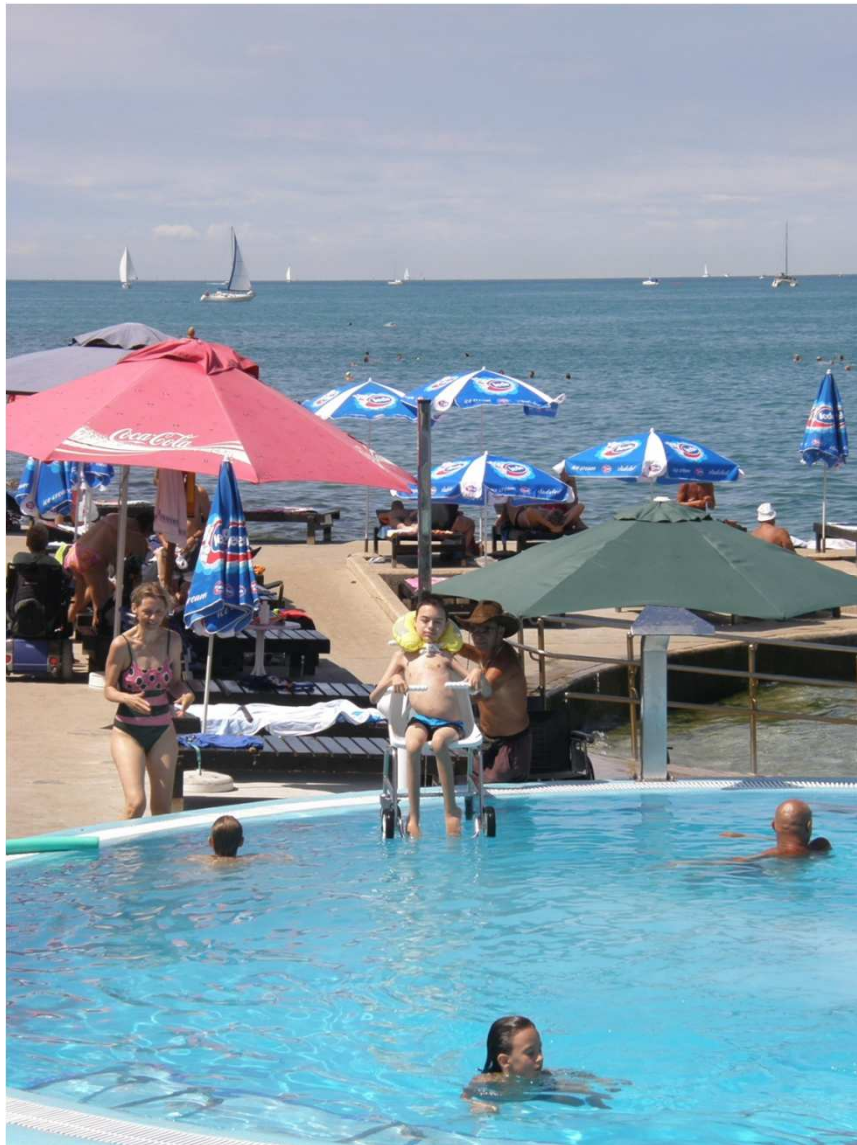
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Results publication entitled “Swimming and other forms of moving in water”



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I. Biological perspectives

Jubilee 40th EAMDA AGM –
opportunity for new ideas on
social and biological perspectives
of persons with NMD in the point
of view for optimistic
expectations for the future. **BUT!**

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I. Biological perspectives

**WE WILL HAVE TO PARTICIPATE
IN THEIR CREATION!**

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Thank you very much for your
attention!

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