



National Conference "Duchenne/Becker Muscular Dystrophy – families and specialists, together for the same cause"

May 8th – 10th 2025, Craiova

Thursday, May 8th

- 08:30 – 09:40** **Participants registration & welcome coffee**
- 09:40 – 10:00** **Opening remarks** – Amelia Dobrescu, Florin Burada (Regional Center for Medical Genetics Dolj, Craiova Emergency County Hospital), Eugenia Roșulescu (Faculty of Physical Education and Sports, University of Craiova), Isabela Tudorache (Parent Project Romania)
- 10:00 – 11:40** **Session I, Moderators: Isabela Tudorache, Filippo Buccella**
- 10:00 – 10:20** **A family perspective** – Filippo Buccella (Parent Project Italia)
- 10:20 – 10:40** **From Compassion to Action – the vision of Parent Project Muscular Dystrophy Romania for research and assistance in Muscular Dystrophy** – Isabela Tudorache (Parent Project Romania)
- 10:40 – 11:00** **More than just a physical condition – recognizing the educational and emotional needs of children and young adults with DMD** – Janet Hoskin (School of Childhood & Social Care, Rix Inclusive Research Institute, University of East London)
- 11:00 – 11:20** **Proactive management of respiratory function in pediatric patients and transition to adults management** – Mihaela Oros (Pediatric Somnology Center, Ponderas Hospital, Bucharest)
- 11:20 – 11:40** **Questions & Discussions**
- 11:40 – 12:00** **Coffee Break**
- 12:00 – 13:40** **Session II, Moderators: Mihai Cucu, Andrada Gheorghe**
- 12:00 – 12:20** **Genetic diagnosis in DMD/BMD** – Florin Burada, Mihai Cucu (Regional Center for Medical Genetics Dolj, Craiova Emergency County Hospital)



- 12:20 – 12:40 Genetic cause and therapeutic eligibility** – Nina Butoianu ("Prof. Dr. Al. Obregia" Psychiatry Hospital, Bucharest)
- 12:40 – 13:00 Evolution from ambulatory to non-ambulatory phase in a patient under exon-skipping therapy** – Mădălina Leanca (National Neuropsychomotor Rehabilitation Center „Dr. Nicolae Robănescu”, Bucharest)
- 13:00 – 13:20 The experience of the National Neuropsychomotor Rehabilitation Center „Dr. Nicolae Robănescu” in the management of neuromuscular diseases** – Andrada Mirea (National Neuropsychomotor Rehabilitation Center „Dr. Nicolae Robănescu”, Bucharest)
- 13:20 – 13:40 Questions & Discussions**
- 13:40 – 14:40 Lunch Break**
- 14:40 – 16:20 Session III, Moderators: Eleodor Cârstoiu, Amelia Dobrescu**
- 14:40 – 15:00 Invasive and non-invasive respiratory support in DMD/BMD** – Alin Pătru (Craiova Emergency County Hospital)
- 15:00 – 15:20 Respiratory support devices** – Constantin Calafeteanu (Vitalaire)
- 15:20 – 15:40 Surgical and orthopedical implications in the therapeutic approach of DMD/BMD patients** – Eleodor Cârstoiu (Craiova Emergency County Hospital)
- 15:40 - 16:00 Physical evaluation and therapy – key-elements in the multidisciplinary care of DMD/BMD patients in a neuromuscular disorders reference center** – Roland Stoica (National Neuropsychomotor Rehabilitation Center „Dr. Nicolae Robănescu”, Bucharest)
- 16:00 – 16:20 Questions & Discussions**
- 16:20 – 16:40 Coffee Break**
- 16:40 – 18:00 Physiotherapy workshop, Moderators: Eugenia Roșulescu, Radu Roșulescu**
- Functional evaluation and rehabilitation of patients with neuromuscular disorders** – Eugenia Roșulescu (Faculty of Physical Education and Sports, University of Craiova)
- Physical exercise in neuromuscular disorders: benefits and limitations** – Denisa Piele (Faculty of Physical Education and Sports, Department of Kinetotherapy and Sports Medicine)



Integrated therapies in muscular dystrophy: formal and non-formal techniques, animal-assisted therapy – Oana Budeancă-Babolea (Faculty of Physical Education and Sports, Department of Kinetotherapy and Sports Medicine), Liviu Ionescu (Global FCI Commission for Rescue Dogs, Romanian-British School)

Fryday, May 9th

- 09:40 – 11:20** **Session IV, Moderators: Alexandru Cărmizaru, Cristina Durac**
- 09:40 – 10:00** **The role of paraclinical investigations in the cardiac management of DMD** – Anda Ungureanu (Craiova Emergency County Hospital)
- 10:00 – 10:20** **Stronger for Longer: choosing the right steroid in DMD** – Cristina Durac (National Institute for Mother and Child Care „Alessandrescu-Rusescu”, Bucharest)
- 10:20 – 10:40** **Review of therapeutic approaches in DMD** – Edoardo Malfatti (Centre de Référence de Maladies Neuromusculaires, APHP Hôpital Henri Mondor, Créteil)
- 10:40 – 11:00** **Red flags at different ages** – Amelia Dobrescu (Regional Center for Medical Genetics Dolj, Craiova Emergency County Hospital)
- 11:00 – 11:20** **Questions & Discussions**
- 11:20 – 11:40** **Coffee Break**
- 11:40 – 13:20** **Session V, Moderators: Edoardo Malfatti, Amelia Dobrescu**
- 11:40 – 12:00** **Neuromuscular diseases, an old concept in a new world** – Amelia Dobrescu (Regional Center for Medical Genetics Dolj, Craiova Emergency County Hospital)
- 12:00 – 12:20** **When to suspect a neuromuscular disease?** – Edoardo Malfatti (Centre de Référence de Maladies Neuromusculaires, APHP Hôpital Henri Mondor, Créteil)
- 12:20 – 12:40** **Muscle histopathology in muscular dystrophies** – Alexandra Bastian (Colentina Clinical Hospital, Bucharest)
- 12:40 – 13:00** **Management update in BMD** – CRGM Dolj neuromuscular team
- 13:00 – 13:20** **Questions & Discussions**



- 13:20 – 14:20** **Lunch Break**
- 14:20 – 16:20** **Sesiunea VI, Moderator: Isabela Tudorache, Ioana Oprea, Ana-Maria Predilă**
- 14:20 – 14:40** **A patient perspective** – Eilon Golan (DMD patient and advocate)
- 14:40 – 15:00** **Exploring Adulthood and Independence in DMD** – Janet Hoskin (School of Childhood & Social Care, Rix Inclusive Research Institute, University of East London)
- 15:00 – 15:20** **Communication inside the multidisciplinary team and the patient-physician relationship** – Ana-Maria Predilă (Media10)
- 15:20 – 15:40** **DMD/BMD Patients Registry** – Alexandru Cărămizaru, Andreea Dumitrescu (Regional Center for Medical Genetics Dolj)
- 15:40 – 16:00** **“Romanian” Neuromuscular Disorders – Neuromuscular Disorders Associations in Romania**
- 16:00 – 16:20** **Questions & Discussions**
- 16:20 – 16:40** **Coffee Break**
- 16:40 – 18:00** **Physiotherapy Workshop, Moderators: Eugenia Roșulescu, Radu Roșulescu**
- Parents or Caregivers? Diving in the trauma of muscular dystrophy families** – Cecilia Mihaela Olteanu (Clinician Psychologist, Personal development counselor)
- Rehabilitation and posture for children and non-ambulatory young adults** – Radu Roșulescu (Clinical Neuropsychiatry Hospital Craiova), Daniela Barbu, Alin Chirea (DGASPC Dolj)
- Kinotherapy and personalized interventions for children and adults** – Eva Ilie (Faculty of Physical Education and Sports, Department of Kinotherapy and Sports Medicine)
- 18:00 – 18:30** **Parent Project Muscular Dystrophy România Meeting, Conclusions**