Editor-in-Chief information

I International Central Asian Congress on Neuromuscular Diseases

"STEP BY STEP ALONG THE SILK ROAD":

Modern Management, Future Prospects, and Interdisciplinary Collaboration

22–24 October 2025, Tashkent, Uzbekistan

The inaugural International Central Asian Congress on Neuromuscular Diseases (NMD) "Step by Step along the Silk Road" convened in Tashkent, uniting specialists from Central Asian countries, Azerbaijan, and Europe. The hybrid-format event gathered 661 registered participants, including 329 in person and 332 online, representing 12 countries.

Organized with the support of the Ministry of Health of the Republic of Uzbekistan, regional scientific centers, and professional medical associations, the Congress also benefited from the partnership of the Institute of Myology (France) and the NGO "Society of Child Neurologists, Neurophysiologists, Psychiatrists, and Psychotherapists" (Kazakhstan).

The Congress focused on:

- advancing diagnostics and therapeutic approaches for neuromuscular diseases (including SMA, DMD, and others);
- strengthening interstate collaboration in neuromuscular medicine;
- promoting early detection and prevention;
- implementing multidisciplinary approaches to patient care;
- enhancing the role of patient organizations and advocacy initiatives.

The scientific program included **10 thematic modules** covering:

- modern diagnostic tools and targeted therapies for SMA and DMD;
- international clinical experience and patient management strategies;
- rehabilitation, respiratory care, and orphan diseases;
- development and support of patient communities.

In total, **49 scientific presentations** were delivered, including 30 lectures by leading experts from France, the United Kingdom, Uzbekistan, Kazakhstan, Azerbaijan, Kyrgyzstan, Georgia, Russia, and other countries.

Pre-Congress Events (22 October)

Two key activities were held:

1. **A school for SMA and DMD patients and families**, covering care, respiratory support, nutrition, orthopedics, vaccination, and other aspects of quality of life.
2. **A practical workshop for neurologists** on the use of functional motor scales for therapeutic monitoring.

Leading specialists from Central Asia, Azerbaijan, and France adopted the concluding resolution to expand clinical cooperation in the diagnosis, treatment, and prevention of neuromuscular diseases, including SMA and DMD. This Congress marked an essential step in establishing a regional professional platform dedicated to advancing neuromuscular medicine and improving access to care.

CONGRESS RESOLUTION

"STEP BY STEP ALONG THE SILK ROAD" ON THE DIAGNOSIS, TREATMENT, AND PREVENTION OF SPINAL MUSCULAR ATROPHY (SMA) AND DUCHENNE MUSCULAR DYSTROPHY (DMD)

The group of experts:

Prof. Shaanvar Shamansurov, MD, DSc
Chief Pediatric Neurologist of the Ministry of Health of the Republic of Uzbekistan;
Chairman, Association of Child Neurologists of Uzbekistan;
Head, Department of Pediatric Neurology named after Prof. Shamansurov Sh.M.;
Center for the Development of Professional Qualifications of Medical Workers;
Chair, Permanent Expert Committee on SMA at the Ministry of Health of Uzbekistan.

Prof. Madina Sharipova, MD, DSc
Chief Geneticist of the Ministry of Health of Uzbekistan; Department of Pediatrics, Tashkent State Medical University; Member, Permanent Expert Committee on SMA, Ministry of Health of Uzbekistan.

Prof. Nodira Tuichibaeva, MD, DSc
Director of the Master's Program in Medical Genetics, Tashkent State Medical University;
Associate Professor, Department of Neurology and Medical Psychology;
President, Association of Clinical Neurophysiologists and Medical Geneticists of Uzbekistan.

Marhabo Shamsiddinova, MD
Republican Specialized Scientific-Practical Medical Center for Maternal and Child Health;
Department of Medical-Genetic Counseling; Neurogeneticist, PhD candidate;
Member, Permanent Expert Committee on SMA at the Ministry of Health of Uzbekistan;
Vice-President, Association of Clinical Neurophysiologists and Medical Geneticists of Uzbekistan.

Umida Omonova, MD, DSc
Associate Professor, Department of Neurology, Pediatric Neurology, and Medical Genetics, Tashkent State Medical University, Uzbekistan

Jamilya Shagiyasova, MD, PhD
Head, Department of Pediatric Neurology, Republican Specialized Scientific-Practical Center of Pediatrics (Uzbekistan); Member, Permanent Expert Committee on SMA at the Ministry of Health of Uzbekistan.

Latina Tekebayeva, MD, PhD
Chief Pediatric Neurologist of the Republic of Kazakhstan; Head, Pediatric Neurology

Program, University Medical Center;Chair, Expert Committee on Pediatric Neurology at the National Center for Orphan Diseases (Kazakhstan, Astana).

Altynshash Jaxybayeva, MD, DSc, Associate Professor
Chief Expert, Department of Clinical Rehabilitation, National Center for Pediatric Rehabilitation; President, Society of Child Neurologists, Neurophysiologists, Psychiatrists, and Psychotherapists (Kazakhstan); Full Member, European Paediatric Neurology Society (EPNS); Executive Committee Member, Asian-Oceanian Myology Center;
(Kazakhstan, Almaty).

Bakhytkul Myrzaliyeva, MSc
Senior Lecturer, Department of Neurology, Kazakhstan-Russian Medical University;
Master of Medical Sciences; Neuromuscular Disorders Coordinator, Almaty;
Member, Expert Committee on Pediatric Neurology at the National Center for Orphan Diseases (Kazakhstan).

Prof. Ayten Mamedbeyli, PhD, DSc
Head, Department of Neurology, Azerbaijan Medical University;
Chief Pediatric Neurology Expert, Ministry of Health of Azerbaijan;
President, Association of Child Neurologists of Azerbaijan (Baku, Azerbaijan).

Ilaha Hajiyeva, MD
Chief Physician, Pediatric Neurology Hospital, Republican Pediatric Center
(Baku, Azerbaijan).

Medina Tagiyeva, PhD
Assistant Professor, Department of Neurology, Azerbaijan Medical University
(Baku, Azerbaijan).

Asel Kadyrova, MD, PhD
Chief Pediatric Neurologist of the Ministry of Health of Kyrgyzstan; WHO Consultant
(Bishkek, Kyrgyzstan).

Nurmuḥamed Babadzhanov, MD, PhD
Pediatric Neurologist, National Center for Maternal and Child Health
(Bishkek, Kyrgyzstan).

International Expert Participants

Dr. Andoni Urtizberea
Institute of Myology;
Director, Myology Summer School (AcadeMYO);
Founder & Chair, Myologie Sans Frontières;
Coordinator, French National SMA Registry Steering Committee;
(Paris, France).

Dr. Edoardo Malfatti, MD, PhD
Chair, Specialized Group on Neuromuscular Pathology, EURO-NMD;
Paris-Est Créteil University
(Paris, France).

PREAMBLE

We, the participants of the I International Central Asian Congress on Neuromuscular Diseases "Step by Step Along the Silk Road," convened in Tashkent (23–24 October 2025):

Recognizing that hereditary neuromuscular diseases—including SMA and DMD—are severe, progressive, and life-threatening genetic disorders that lead to early disability and significantly reduce life expectancy and quality of life, imposing a considerable burden on families and society;

Acknowledging the pressing regional challenges, including low public and professional awareness, late diagnosis, uneven and limited access to modern diagnostics and therapies, high treatment costs, uncertainties regarding therapeutic effectiveness, and the absence of a comprehensive multidisciplinary care system;

Emphasizing the necessity of uniting the efforts of the medical community, government institutions, patient organizations, and society to substantially improve medical and social support for individuals with hereditary neuromuscular diseases;

Guided by the principles of the Universal Declaration of Human Rights, the Convention on the Rights of the Child, and the United Nations Sustainable Development Goals, which uphold the right to health and human dignity, as well as the WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022–2031 (IGAP);

Hereby adopt this Resolution, which outlines the key strategic directions for joint coordinated action.

KEY AREAS OF ACTION

FOR CENTRAL ASIAN COUNTRIES (UZBEKISTAN, KAZAKHSTAN, KYRGYZSTAN) AND AZERBAIJAN

1. Diagnostics and Early Detection

- Promote the introduction and expansion of neonatal and/or selective screening programs for SMA and DMD as highly effective tools for preclinical detection.
- Recommend harmonizing national policies, clinical protocols, and diagnostic algorithms to ensure timely referral to neurologists and geneticists.
- Advocate the establishment of genetic reference laboratories providing confirmatory DNA diagnostics using modern technologies (PCR, MLPA, NGS, etc.) within the member countries.
- Enhance awareness among primary-care physicians through training programs aimed at recognizing early signs of SMA and DMD.
- Support broad educational initiatives for the population, healthcare workers, and health administrators to raise awareness of neuromuscular diseases and the importance of early diagnosis and innovative treatments.

2. Treatment and Therapeutic Monitoring

- Encourage governments and health authorities to consider including pathogenetic therapies for hereditary neuromuscular diseases, including SMA and DMD, in state-funded drug programs, taking into account global experience and recommendations.
- Develop and approve clear criteria for initiating, continuing, or discontinuing therapy, along with mechanisms to ensure patient adherence and caregiver responsibility.
- Emphasize the importance of establishing Myology Schools to support a multidisciplinary approach, involving neurologists, pulmonologists, intensivists, cardiologists, orthopedists, physiotherapists, dietitians, and psychologists.
- Support the creation and accreditation of specialized expert centers equipped for comprehensive management of patients with hereditary neuromuscular diseases.
- Develop and implement unified regional clinical guidelines for patient monitoring, including motor, respiratory, cardiac, and nutritional assessments.
- Promote the adoption of preclinical therapeutic interventions to maximize treatment outcomes.
- Develop and implement structured transition protocols for transferring patients from pediatric to adult care.
- Encourage collaboration among governments, non-profit organizations, and pharmaceutical companies to ensure sustainable funding for treatment and rehabilitation programs, particularly in resource-limited settings.

3. Rehabilitation, Long-Term Support, and Palliative Care

- Recognize rehabilitation as an essential component of care for SMA and DMD and ensure continuity and accessibility throughout the patient's lifespan.
- Standardize physical, respiratory, and occupational therapy approaches by adapting international protocols to regional needs.
- Advocate for national rehabilitation programs with regular physiotherapy, respiratory training, adapted physical activities, and caregiver education.
- Ensure timely provision of assistive technologies (wheelchairs, orthoses, braces, corsets, standing frames) and respiratory support equipment (NIV devices, cough-assist equipment, Ambu bags, pulse oximeters, aspirators, tracheostomy supplies).
- Promote integrated psychological and social support, including educational seminars, parental training, support groups, and caregiver skill development.
- Support the expansion of palliative care programs aimed at improving quality of life at all stages of the disease.

4. Prevention and Control of SMA and DMD Prevalence

- Develop and maintain national SMA and DMD patient registries to improve epidemiological monitoring, resource allocation, research capacity, and access to therapy.
- Recommend genetic testing for family members of affected individuals to identify carriers and support informed family planning.
- Encourage prenatal invasive diagnostics and the use of assisted reproductive technologies for high-risk families.
- Support carrier screening programs (premarital, preconception, early pregnancy) to promote informed reproductive choice and enable timely intervention.
- Recommend including hereditary neuromuscular diseases in national rare disease strategies with dedicated funding, grants, and state support programs.

5. Research and Innovation

- Encourage clinical and fundamental research on hereditary neuromuscular diseases, including SMA and DMD, across Central Asia and Azerbaijan.
- Promote the creation of international and regional research consortia to share data and conduct collaborative clinical studies, particularly on advanced therapies.
- Support active involvement of patients and patient representatives in research initiatives, clinical registries, and treatment program development.
- Recognize the importance of international partnerships with leading global centers and organizations.
- Promote cooperation among governments, academic institutions, patient organizations, and pharmaceutical companies to ensure sustainable development of diagnostic and therapeutic capabilities.
- Strengthen collaboration with international professional associations (World Muscle Society, TREAT-NMD, SMA Europe, International Alliance of SMA, Asian Oceanian Myology Center).
- Emphasize the need to hold the "Step by Step Along the Silk Road" Congress biennially to maintain knowledge exchange and regional coordination.
- Unanimously agree to hold the next Congress in 2027 in Kyrgyzstan.

6. Patient Community Support

- Recognize the essential role of patient organizations in safeguarding patient rights, raising awareness, and supporting families.
- Promote dialogue between patient organizations and government authorities to inform health policy decision-making.
- Support public awareness initiatives aimed at reducing stigma and fostering an inclusive environment for individuals with SMA and DMD.

CONCLUSION

The participants of the Central Asian Congress "STEP BY STEP ALONG THE SILK ROAD" call upon all stakeholders—healthcare professionals, ministries of health, scientific institutions, patient organizations, and international partners—to jointly implement the provisions of this Resolution.

We reaffirm our collective commitment to improving the diagnosis, treatment, and prevention of hereditary neuromuscular diseases, including SMA and DMD, in Central Asian countries and Azerbaijan, with the goal of reducing the burden on patients, families, society, and healthcare systems.

We pledge to work together—physicians, researchers, patient families, and governments—step by step, along the Silk Road, to ensure equitable access to high-quality care for all children and adults in need.

We call upon regional governments, international organizations, and pharmaceutical companies to support these initiatives and contribute to the sustainable development of neuromuscular disease programs.

We are confident that through coordinated and purposeful joint efforts, we can make substantial progress in improving the quality and longevity of life for people living with hereditary neuromuscular diseases across Central Asia and Azerbaijan.