

PROGRAMME

II International Conference: “ Vital Problems in Providing Medical Care for Patients with MPS and Other Rare Genetic Diseases”

Date: 24-25 October, 2013.

Venue: “Mother and Child” NRC , Assembly Hall; 66, Orlovsky Str., Minsk, Republic of Belarus

Registration: 24-25 October, 2013 - 8.30 -9.30



October 24 , 2013 (1st day)

Time	Report	Person
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Presidium: Ye.L.Bogdan - Head of the Main Department for organization of medical care, Ministry of Health, Belarus; Ye.A.Lekhaya - Chief, Department of medical assistance to mothers and children; Prof. A.Tilki-Shimanska, National Child Care Center, Warsaw, Poland



09.30-09.45	Opening Ceremony	Pinevich D.L.- First Deputy Minister of Health, Belarus
09.45-10.00	Greetings	Matievich T.N.- nPresident of NPA “Belarussian organization of patients with MPS and other rare diseases”
10.00-10.30	“Pompe’s disease	Prof.A.Tilki-Shimanska , National Child Care Center, Warsaw, Poland
10.30-11.00	Orthopedic pathology in patients with MPS	Prof. Mikhailova L.K., N.N.Priorov Central Research Institute of Traumatology and Orthopedics, Moscow, Russia
11.00-11.30	Perspectives for treatment of neurological disorders in LSDs.	Maurizio Scarpa MD PhD. Department of pediatrics, University of Padua , Italy
11.30-12.00	Coffee break	



Presidium: Trukhanovich V.I.,- Chief Pediatrician of the Ministry of Health, Belarus
Naumchik I.V.- Deputy Director on Medical Genetics, "Mother and Child" NRC,Minsk

12.00-12.30	Fabry's syndrome	Laila.Arash-Kaps Geb. Arash , University Clinic, Villa Metabolica, Mainz, Germany.
12.30-13.00	Efficacy of ERT, management and follow up, examination of patients with MPS VI	Christina Lampe , University Clinic, Villa Metabolica, Mainz, Germany
13.00-13.30	Metachromatic leucodystrophy as a paradigm of neurometabolic diseases	Agnieszka Lugovska , National Child Care Center , Warsaw, Poland
13.30-14.30	Lunch	
14.30-15.00	Mucopolysaccharidoses. Clinical diversity of phenotypes. Current approaches to treatment.	Prof.A.Tilki-Shimanska. , National Child Care Center, Warsaw, Poland
15.00-15.30	MPS as a multisystemic disease - role of physiotherapy in diseases' outcome	Jolanta Marucha , National Child Care Center, Warsaw, Poland
15.30-16.00	"Gauscher's disease. Progressive lymphadenopathy against ERT	Lapotentova E.S. , Chief of Department, "Pediatric Oncology, Hematology and Immunology" NRC, Minsk
16.00-16.30	Remedial tactics of metabolic disorders in children with hereditary diseases of organic acid metabolism.	Nickolayeva E.A. , Doctor of Medical Sciences, Geneticist, Department of congenital and inherited diseases, Moscow Research Institute of Pediatrics and Child Surgery
16.30-16.50	Neonatal diabetes	Solntseva A.V. , Chief Pediatric Endocrinologist, Ministry of Health, Belarus
16.50-17.00	Rehabilitation of children with the disease MPS	Sorova E.M. Instructor-methodologist. RDHMR



October 25, 2013 (2nd day)

Presidium: E.A. Ye.A.Lehkaya - Chief, Department of medical assistance to mothers and children;
N.B.Gusina - Chief of Clinical diagnostic genetic laboratory, "Mother and Child"NRC, Minsk

Time	Report	Person
		
09.30-09.40	Opening	Naumchick I.V. , Deputy Director on Medical Genetics, "Mother and Child"NRC, Minsk
09.40-10.10	Metabolic diseases in the newborn	Prof.A.Tilki-Shimanska , National Child Care Center, Warsaw, Poland
10.10-10.40	Glycogen disease	Gusina N.B. , Chief of Clinical diagnostic genetic laboratory, "Mother and Child"NRC, Minsk
10.40-11.10	Orthopedic aspects with osteogenesis imperfecta	Prof.Sokolovsky O.A. , "Traumatology and Orthopedics" NRC
11.10-11.30	Differential diagnosis of neurodegenerative diseases. A clinical case report	Zhevneronok I.V. , Assistant, Pediatric Neurology Department, Belarusian Medical Academy of Postgraduate Education(BelMAPE)
11.30-12.00	Coffee break	
		
12.00-12.15	Diagnosis and management of Gausher's disease in Lithuania	Grazhina .Kleinotiene , Oncology and Hematology Center, Children's Hospital of Vilnius University, Lithuania
12.20-12.35	Lesch-Nyhan syndrome. A family case report	Yakovlev A.N. ,Neurologist, Psychoneurology Department No.1 , Minsk State Center of Medical Rehabilitation

12.35-12.55	A case report	Rumyantseva N.V. , Leading researcher, "Mother and Child" NRC, Minsk
12.55 - 13.15	Molecular and genetic diagnosis in adreno-genital syndrome.	Demidovich T.V. , Clinical diagnostic genetic laboratory, "Mother and Child" NRC
13.15-13.30	Nizhmegen Syndrome	Smirnova O.Ya. , Geneticist, Mogilev Regional Treatment and Diagnostic Center, Belarus
13.30-14.30`	Lunch	

Presidium: Ye.L.Bogdan, Head of the Main Department for organization of medical care, Ministry of Health, Belarus; Naumchick I.V., Deputy Director on medical genetics, "Mother and Child" NRC, Minsk



14.30-14.50	Mitochondrial depletion syndrome, diagnostic experience in Belarus	Zinovick A.V. Clinical diagnostic genetic laboratory, "Mother and Child" NRC, Minsk
14.50-15.10	CDG-syndrome. A case report.	Kalinina Ye.A. Chief, Department of medical genetic counseling, "Mother and Child" NRC, Minsk
15.10-15.30	Leigh-syndrome, features of clinical manifestations at different ages	Zobikova O.L. , Researcher, "Mother and Child" NRC, Minsk
15.30-15.50	Spinal amyotrophy. Kugelberg-Willander type	Golubeva S.V. , Chief, Department of medical genetic counseling, Vitebsk Diagnostic Center, Belarus.
15.50-16.10	Ectodermal dysplasia. A family case report	Motyuk I.N. Geneticist., "Grodno Clinical Perinatal Center", Belarus
16.10- 16.30	Tactics in diagnosing rare genetic diseases	Naumchik I.V. , Deputy Director on medical genetics, "Mother and Child" NRC. Minsk
16.30-17.00	Summing-up Closing ceremony	Pinevich D.L. , First Deputy Minister, Ministry of Health , Belarus

End of the conference



October 25, 2013 (2nd day)

Session for patients with a representative of the Ministry of Health



Welcome to the patients and their families



Patients and their families



Acknowledgements for participation and completion of the conference