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VAIKŲ LIGONINĖ
VšĮ Vilniaus universiteto ligoninės Santaros klinikų filialas



IXth INTERNATIONAL SCIENTIFIC CONFERENCE “INNOVATIONS IN THE MANAGEMENT OF RARE DISEASES“

CONFERENCE VENUE: CROWNE PLAZA VILNIUS (M.K. ČIURLIONIO STR. 84, VILNIUS)

16 MARCH 2018

09:00–09:30	Registration
Chairs: Prof. Rimantė Čerkauskienė, gyd. Elena Jurevičienė	
09:30–10:00	Welcome and opening Ministry of Health; Ministry of Education and Science; Ministry of Social Security and Labour; VUH Santaros Klinikos; EURORDIS representatives
10:00–10:30	Implementation of national rare disease activities in Lithuania Kristina Garuolienė, Anželika Balčiūnienė, Ministry of Health representative
10:30–10:45	Patient organization activities: 2 years experience and further aspirations Danas Čeilitka, president of the National Rare Diseases Alliance
10:45–11:00	Special educational needs of patients with rare diseases Gražina Šeibokienė Ministry of Education and Science
11:00–11:15	Social care for patients with rare diseases and their relatives Ministry of Social Security and Labour representative
11:15–11:35	Coffee break
Chairs: gyd. Elena Jurevičienė, dr. Birutė Tumienė	
11:35–12:00	Coordination of rare disease activities in Czech Republic: National Coordination centre for rare diseases Prof. Milan Macek, Prague, Czech Republic
12:00–12:20	EURORDIS: role of rare disease patient organizations Ariane Weinman, EURORDIS, Italy
12:20–12:45	Coordination of rare disease activities in VUH Santaros Klinikos Prof. Rimantė Čerkauskienė, MD Elena Jurevičienė, VUH Santaros Klinikos
12:45–13:00	Review of rare diseases national plans and strategies in Europe MD Phd Birutė Tumienė, VUH Santaros Klinikos
13:00–13:30	Discussions, conclusions, suggestions for memorandum, formation of memorandum work group
13:30–14:30	Lunch
14:30–18:00	Parallel sessions
<p>TOGETHER WE CAN ACHIEVE MORE (SPINA BIFIDA) Patient organizations and medical staff discussions (Lithuanian and English) Chair: Rūta Udraitė-Mikalauskiene, Danas Čeilitka</p>	
14:30- 14:45	Rehabilitation clinic “Spinalis” (Stockholm, Sweden): multidisciplinary approach to rehabilitation of adults with spinal cord injury. Vilija Šatienė, member of SBH association administration
14:45-15:00	Functional mobility possibilities in children with spina bifida. Elena Slobodyanik, chairperson of SBH association

15:00-15:30	Overview of Spina Bifida and Hydrocephalus patients multidisciplinary care systems in Europe. Janina Arsenjeva, The International Federation for Spina Bifida and Hydrocephalus (IF), Europe Programme Manager, Belgium
15:30- 16:00	Prevention and management of secondary health conditions in children with Spina Bifida: a systematic approach. Marit Rekkedal Edvardsen, physical therapist, Akershus university hospital, Norway
16:00-16:30	Coffee break
16:30-17:00	Methods and measures used in follow-up programs in Norway in relation to maintaining renal function. Using aid and medication to get the best possible control Vibeke Haahr, urotherapist, Akershus university hospital, Norway
17:00-17:15	Psychosocial approach to rehabilitation, Kaunas Clinics Pediatric rehabilitation clinic "Lopšelis" experience. Indrė Bakanienė, Pediatric rehabilitation clinic „Lopšelis“, head of the department, pediatric neurologist
17:15-17:30	Neuropsychological features of spina bifida Rūta Vyšniauskė, Children's Hospital VUH Santaros Klinikos
17:30 -18:00	Gait assessment and correction in children. Dr. Aurelijus Domeika, head of KTU Institute of Mechatronics Biomechanics laboratory; Eugenijus Mačiukas, „Aurelka“ orthopedic shoes representative for Baltic states

THE FIRST STEP: DIAGNOSTICS OF RARE DISEASES

Genetics (English)

Chair: prof. Algirdas Utkus

14:30-15:00	3D facial gestalt analysis in dysmorphology. Prof. Milan Macek, Prague, Czech Republic.
15:00-15:20	Preimplantation genetic diagnostics - Lithuanian status. Dr. Laima Ambrozaitytė, Kristina Grigalionienė, VUH SK
15:20-15:40	Strategies of stem cell use in regenerative medicine. Dr. Eiva Bernotienė, Centre for Innovative Medicine
15:40-16:00	Clinical applications in pharmacogenetic testing. Karolis Baronas, VUH SK
16:00–16:20	Coffee break
16:20–16:40	Dysmorphology today. Dr. Aušra Matulevičienė, VUH SK
16:40-17:00	The use of artificial intelligence in rare disease diagnostics. Karolis Šablauskas, VUH SK
17:00–17:20	Genomic testing in epilepsy diagnostics. Dr. Birutė Tumienė, VUH SK
17:20-17:40	Molecular karyotyping: clinical utility and practice. Deimantė Braždžiūnaitė, VUH SK
17:40-18:00	Discussions

PATH TO THE FUTURE: A NEW APPROACH TO RARE DISEASES

Science and innovations (Lithuanian and English)

Chair: prof. Augustina Jankauskienė

14:30-15:00	Novel insights in CKD and PD induced alterations of the peritoneal membrane. Betti Shaefer, Germany.
15:00-15:20	DGKE nephropathy: a new form of hemolytic uremic syndrome. Karolis Ažukaitis, Vilnius University Faculty of Medicine
15:20-15:40	Gene engineering and synthetic biology methods to treat rare diseases prior to their manifestation. Gabrielius Jakutis, Vilnius University Faculty of Medicine, Vilnius-Lithuania iGEM, Society of Innovative Medicine
15:40-16:10	Cognitive function in children with spina bifida and the results of pilot study on goal management training. Dr. Marie Hoff, TRS National Resource Centre for Rare Disorders, Sunnaas Hospital, Norway
16:10-16:30	Coffee break
16:30-16:50	Atypical Presentation of Griscelli Type 2 Syndrome: Lithuanian Experience Dr. Jelena Rascon, Children's Hospital VUH Santaros Klinikos
16:50-17:10	Batten disease. Asta Judickienė, MD, Children's Hospital VUH Santaros Klinikos
17:10-17:30	Rare types of diabetes. Assoc. prof. Evalda Danytė, LUHS Kaunas Clinics
17:30-18:00	Discussions