Co-funded by the Health Programme of the European Union

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
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	Lithuanian national rare diseases plan: accomplished tasks and future challenges 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
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
TOGETHER WE CAN ACHIEVE MORE (SPINA BIFIDA) Patient organizations and medical staff discussions (Lithuanian and English) Chair: Rūta Udraitė-Mikalauskienė, Danas Čeilitka	
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

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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 Biomechatronics 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 Bražd̄iūnaitė, 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