



VAIKŲ LIGONINĖ
VŠĮ Vilniaus universiteto ligoninės Santaros klinikų filialas



RETŲ LIGŲ
FONDAS

VIIITH SCIENTIFIC PRACTICAL CONFERENCE, DEDICATED TO THE RARE DISEASES DAY “COORDINATING CENTRE FOR CHILDREN’S RARE DISEASES – EXPERIENCE AND ACHIEVEMENTS IN 5 YEARS”

March 1st, 2018

CHILDREN'S HOSPITAL, VUH SK, SANTARIŠKIŲ 7, LARGE AUDITORIUM | 10:00 – 17:00

09:30-10:00	Registration
10:00-10:20	Opening speech. Vilnius University Faculty of Medicine dean, VUH SK administration, Ministry of Health representatives
10:20-10:40	New approach to rare diseases. Prof. R. Čerkauskienė, Coordinating Centre for Children's Rare Diseases, Children's Hospital, VUH SK
10:40-11:10	Representatives of patient organisations: President of National Rare Diseases Alliance D. Čeilitka, representative of Spina Bifida and Hydrocephalus Association R. Udraitė-Mikalauskienė, head of National MPS and Other Metabolic Diseases Association R. Šliuožaitė
11:10-11:30	Genetic testing possibilities in Lithuania. Prof. A. Utkus, Medical Genetics Center, VUH SK
11:30-11:50	Vaccination of patients with rare diseases. Prof. V. Usonis, Clinic of Children's Diseases, Vilnius University Faculty of Medicine
11:50-12:10	Rare disease patient family's participation in treatment and decision making. Dr. S. Burokienė, Children's Hospital, VUH SK
12:10-12:30	Coffee break
12:30-12:45	Rare pediatric kidney diseases – can family physician help? Prof. A. Jankauskienė, Competence center for rare kidney disorders and congenital anomalies of the urogenital tract, VUH SK
12:45-13:00	Lysosomal storage diseases – when to suspect? Prof. R. Čerkauskienė, Competence center for lysosomal storage diseases, VUH SK
13:00-13:15	National and international initiatives for severe familial dyslipidemias: review and Lithuanian experience. Prof. Ž. Petruilionienė, Competence center for lipidology, Children's Hospital, VUH SK
13:15-13:30	How far can one get when you know where you are going? Dr. J. Rascon, Competence center for pediatric oncology, hematology and cancer surgery, Children's Hospital, VUH SK
13:30-14:10	Lunch
14:10-14:30	Comprehensive care of rare coagulation disorders. Dr. S. Šaulytė-Trakymienė, Competence center for hemophilia and coagulation disorders, Children's Hospital, VUH SK
14:30-14:45	Rare pediatric neuromuscular disorders – what's new? Doc. J. Grikinienė, Competence center for pediatric neuromuscular disorders, Children's Hospital, VUH SK
14:45-15:00	Pediatric epilepsy and sleep disorders diagnostics and treatment news. Dr. R. Praninskienė, Competence center for children with epilepsy and sleep disorders, Children's Hospital, VUH SK
15:00-15:15	Pediatric HIV infection in Lithuania. Dr. I. Ivaškevičienė, Children's Hospital, VUH SK
15:15-15:35	Coffee break
15:35-15:50	Long term parenteral nutrition complications. Doc. V. Urbonas, Competence center for rare pediatric liver diseases, enteral and parenteral nutrition, Children's Hospital, VUH SK
15:50-16:05	Rare rheumatic and autoinflammatory diseases – unforgettable patients. Dr. R. Rusonienė, Competence center for pediatric rheumatic and autoinflammatory diseases, Children's Hospital, VUH SK
16:05-16:20	Acute metabolic diseases: first symptoms and outcomes. B. Burnytė, MD, Competence center for inborn errors of metabolism with acute onset in newborn and child, Children's Hospital, VUH SK
16:20-16:40	Benefits of genetic testing in epilepsy patients. Dr. B. Tumienė, Medical Genetics Center, VUH SK
16:40-17:00	Discussions