

המרכז הרפואי שיבא תל השומר, צוות המכון למחלות נדירות והמכון הגנטי,
מתכבדים להזמין אתכם לכנס בנושא:

Bridging Health and Social Care

יום המחלות הנדירות הבינלאומי 2019
INTERNATIONAL RARE DISEASE DAY 2019

Thursday 28.02.19 08:00 AM

באולם בית סוראסקי, המרכז הרפואי שיבא, תל השומר

- 08:00-09:00** **Welcome**
- 09:00-09:30** **Opening Greetings**
Prof. Yitshak Kreiss Director General, Sheba Medical Center, Tel Hashomer
Dr. Itai Pessach Director of the Edmond and Lily Safra Children's Hospital, Sheba Medical Center, Tel Hashomer
Prof. Elon Pras Director, The Danek Institute for Human Genetics, Sheba Medical Center, Tel Hashomer
Dr. Hadar Yardeni Director of the Department of Child Development & Rehabilitation, Ministry of Health, Jerusalem
- 09:30-09:45** **M.K. Yoav Kisch** Chairman of the Internal Affairs and Environment Committee
Rare Disease Law in Israel
- 09:45-10:30** **Prof. Nicolas Levy** Département de Génétique Médicale et Biologie Cellulaire, Hôpital d'Enfants La Timone; Inserm UMR_S 1251, Marseille Medical Genetics Center, Faculty of Medicine, Marseille, France
Pathophysiology and Therapeutic Developments in Progeroid Syndromes
- 10:30-10:50** **Dr. Shoshana Greenberger** Pediatric Dermatology Service; The Department of Dermatology, Sheba medical Center, Tel Hashomer
Vascular Anomalies: From Genetics Towards Novel Treatments
- 10:50-11:10** **Prof. Polina Stepensky** Director, Department of Bone Marrow Transplant and Cancer Immunotherapy, Hadassah Hebrew University Hospital, Jerusalem
Unraveling Novel Immune Deficiency Syndromes: Pathways from Patients to Bench and Bone Marrow Transplant
- 11:10-11:30** **Dr. Mauritz Beeri** Director General, Alyn Hospital Rehabilitation Center, Jerusalem
Childhood, Disability and Reality-Pediatric Rehabilitation in an Evolving Environment
- 11:30-12:00** **Coffee Break**
- 12:00-12:20** **Mrs. Tali Kaplan** Founder & CEO Little Steps Association for DMD & BMD
Living with Duchenne-Becker Muscular Dystrophy
- 12:20-12:40** **Prof. Yaacov Frishberg** Director, Division of Pediatric Nephrology, Shaare Zedek Medical Center, Jerusalem
Primary Hyperoxaluria type 1 - Novel Therapeutic Approaches
- 12:40-13:00** **Dr. Galit Tal** Metabolic Clinic, The Ruth Rappaport Children's Hospital Rambam Medical Center, Haifa
Alpha Mannosidosis - Treating a Rare Disease with Limited Information
- 13:00-13:20** **Dr. Ido Didi Fabian** Consultant Ocular Oncologist; Goldschleger Eye Institute, Sheba Medical Center, Tel Hashomer
Global Retinoblastoma Presentation
- 13:20-13:30** **Prof. Annick Raas-Rothschild** Director, The Institute for Rare Diseases, The Danek Institute for Human Genetics, Sheba Medical Center, Tel Hashomer
Summary
- 13:30-15:00** **Lunch**