

המרכז הרפואי שיבא וצוות המכון למחלות נדירות מתכבדים להזמין אתכם

# The Sixth International Rare Disease Day

## A rare disease is diagnosed - what's next?

### Thursday 27.2.20 08:30 AM

באולם בית סוראסקי, המרכז הרפואי שיבא, תל השומר

**08:30-09:00 Welcome**

**09:00-09:25 Greetings**

Prof Arnon Afek, Associate Director and Acting Director of General Hospital, Sheba Medical Center  
Dr Itai Pessach, Director, Lily and Edmond Safra Children Hospital, Sheba Medical Center  
Prof Elon Pras, Head, Human Genetics Institute, Sheba Medical Center

**09:25-09:35 Rare Diseases: Challenges and Changes**

Prof Annick Raas - Rothschild, Head, Rare Disease Institute, Lily and Edmond Safra Children Hospital, Sheba Medical Center

**09:35-10:05 New Perspectives on The Treatment of Skeletal Dysplasia**

Prof Valerie Cormier - Daire, Head, Institute IMAGINE - Hopital Necker - Enfants Malades, Paris, France

**10:05-10:30 Parent Perspective From a Patient Perspective**

Mr Gary Grinspan, Business & Social Entrepreneur

**10:30-11:00 Coffee Break**

**11:00-11:20 Doctor - Patient Relations in The Age of Data: The Rules of The Game Have Changed**

Roy Keidar, Co - founder of Medint and former CEO of the Reut Group for strategic planning

**11:20-11:40 The CHD4 - related Disorder, Understanding a New Syndrome**

Dr Karin Weiss, Genetics Institute Rambam Health Care Campus

**11:40-12:00 Combining Multidisciplinary Academic - Patient - Pharma - Biotech Efforts to Develop Treatments for Ultra - Rare Diseases - The Story of Andlit**

Dr. Yael Gruenbaum Cohen, CEO Andlit Therapeutics & Director Medison Ventures

**12:00-12:20 Accelerating the Road for Treatment of Rare Diseases: ACTA2**

Dr Omer Bar Yossef, Pediatric Neurology and Child Development & Deputy Director, Edmond and Lily Safra Children Hospital, Sheba Medical Center  
Dr Shane Wald Altman, CTO and Co-founder of QRGenetics

**12:20-12:40 Awareness - Key to Diagnose a Rare Disease**

Dr Meirav Segev, Human Genetics Institute, Sheba Medical Center

**12:40-13:00 Panel: Reframe Rare**

Mr Tal Karo, Moderator

Dr Hadar Yardeni, Head of the Department of Child Developmental and Rehabilitation Ministry of Health

Mrs Keren Avni, Mother to a child living with a rare disease

Mr Shmulik Ben Yaacov, The Association for Patients' Rights, Chairman

Mrs Orly Dror-Azurriel, Association for fighting A-T disease, Chairman

Ruthie Hostovsky Raz, Adv, Director of Health Rights Law Clinic, IDC Herzlia

Dr Dvir Dahary, Geneticist

**13:00-14:00 Lunch**