

EMPOWERING LIVES: RARE DISEASES IN THE EVOLVING MALTESE SOCIETY

Under the Auspices of Her Excellency, Dr Myriam Spiteri Debono

President of the Republic of Malta

28th February 2025

Venue: Verdala Palace, L/O Buskett, Malta

Registration and welcome coffee	08:30 – 09:00	
Hon Jo Etienne Abela Minister for Health & Active Ageing	09:00 – 09:05	Opening Speech
Mr Clarence Pace Chief Medical Officer	09:05 – 09:10	Rare Diseases Day
Ms Michelle Muscat	09:10 – 09:15	Rare Diseases
Prof Alex E Felice K.M.	09:15 – 09:20	Introductory Speech

Plenary Session I

Dr Anthony Gatt	09:25 – 09:35	Cross-border Healthcare Directive
Dr Lara Wilma Borg	09:35 – 09:50	Rare Diseases - Differences between the Maltese residents and Foreign Residents
Dr Silvana Masi	09:50 – 10:10	Luxembourg experience: Implementation of ERNs service in a small country
Mr Antoni Montserrat Moliner	10:10 – 10:20	Rare diseases experience in Luxembourg
Ms Angelea Sultana	10:20 – 10:30	Personal experience
Plenary discussion	10:30 – 10:50	Panel
<i>Dr Miriam Azzopardi</i>		
<i>Dr Silvana Masi</i>		
<i>Mr Antoni Montserrat Moliner</i>		
<i>Ms Michelle Muscat</i>		
Chair: <i>Ms Gertrude Buttigieg</i>		
Coffee break	10:50 – 11:15	

Plenary Session II

Dr Antonio Gonzalez-Meneses	11:15 – 11:40	Holistic Picture of Rare Diseases and Diagnosis
Mr Rosario Mizzi	11:40 – 11:55	SLP experience with rare diseases
Dr James Clark	11:55 – 12:10	The ERN experience for Maltese Healthcare
Dr Julian Delicata	12:10 – 12:20	ERN Clinician experience
Mr Luca Vella	12:20 – 12:30	Personal experience
Plenary discussion	12:30 – 13:00	Panel
<i>Dr James Clark</i>		
<i>Mr Rosario Mizzi</i>		
<i>Dr Antonio Gonzalez-Meneses</i>		
<i>Dr Julian Delicata</i>		
Chair: <i>Mr Oliver Scicluna</i>		
Standing Lunch	13:00 – 14:15	

Plenary Session III

Advances in Rare Disease Medicine

Professor Ing. Simon Fabri	14:30 – 14:40	Opening Remarks
Prof Joseph Borg	14:40 – 14:50	Introducing the Reference Genome of Malta
Prof Jim Bonham	14:50 – 15:10	Newborn screening in Europe: the challenges and the opportunities
Ms Ruth Galdies and Prof Christian Scerri	15:20 – 15:30	After the Thalassaemia Project: Further Development of Newborn Testing in Malta
Dr Daria Julkowska	15:30 – 15:40	The European Rare Diseases Research Alliance: empowering rare diseases research community
Dr Tobias Fleischmann	15:40 – 15:50	Exploring the Potential of Gene Therapy in Rare Disease Treatment: Prospects and Problems
Ms Maria Vella	15:50 – 16:00	Does Space-Omics Reveal Innovative Therapeutic Targets for Gene Therapy in Rare Disease?