

EUROPEAN REFERENCE NETWORKS

WORKSHOP FOR
INFORMATION AND
EXCHANGE

14
01
19

Room:
Solon Triantafyllides,
Bank of Cyprus
Head Office, Nicosia,
Cyprus

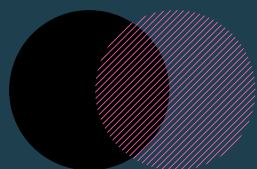


Partners



NATIONAL COMMITTEE
FOR RARE DISEASES
CYPRUS





PROGRAMME

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- 9:00 - 9:30 AM** **REGISTRATIONS**
- 9:30 - 9:50 AM** **SPEECHES**
Dr. Androulla Eleftheriou, President of the Cyprus Alliance for Rare Disorders
Dr. Stavros Malas, Professor of Mammalian Developmental Neuroscience and Genetics,
University of Nicosia Medical School
Dr. Christina Yiannaki, Permanent Secretary of the Ministry of Health of Cyprus / President
of the National Committee for Rare Diseases
Mr. Demetris Syllouris, President of the House of Representatives – Parliament of Cyprus
- 9:50 - 10:05 AM** **Cyprus' participation in the European Reference Networks**
Dr. Olga Kalakouta, Ministry of Health
- 10:05 - 10:20 AM** **European Health Policies with relevance to Rare Disorders**
Dr. Androulla Eleftheriou, President of the Cyprus Alliance for Rare Disorders
- 10:20 - 10:35 AM** **Patients' Rights in the framework of cross-border healthcare**
Ms. Despo Olympiou, Ministry of Health
- 10:35 - 10:50 AM** **Centres of Expertise and Excellence: Challenges but also opportunities for the management
of Rare Disorders**
Professor Leonidas A. Phylactou, Chief Executive Medical Director, The Cyprus Institute of
Neurology and Genetics (CING)
- 10:50 - 11:05 AM** **Cyprus Thalassaemia Centre: Our participation in the EuroBloodNet (European Reference
Network on Rare Hematological Diseases)**
Dr. Soteroula Christou, Clinical expert, Thalassaemia Centre of Nicosia, Cyprus
- 11:05 - 11:15 AM** **Rare e-Connect: A Telecollaboration platform for medical professionals and best practice
exchange for the management of Rare Disorders**
Dr. Victoria Antoniadou, Cyprus Alliance for Rare Disorders
- 11:15 - 12:00 PM** **European References Network (ERNs) State of Play**
Mr. Matt Johnson, ERN and Healthcare Advisor, EURORDIS
- 12:00 - 12:45 PM** **Discussion - Coordination**
Dr. Stavros Malas, Dr. Androulla Eleftheriou, Mr. Matt Johnson
- 12:45 - 13:00 PM** **Conclusions**
Dr. Christina Yiannaki, Permanent Secretary of the Ministry of Health of Cyprus / President
of the National Committee for Rare Diseases
- 13:00 - 14:00 PM** **LUNCH**