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UNIVERSITÀ
DEGLI STUDI
DI PADOVA



ANNUAL CONVENTION ON RARE DISEASES

CITY OF PADUA

Online Edition
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www.malattierarepadova.it

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R&I GENETICS

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WEDNESDAY, FEBRUARY 24TH 2021

FOUR WEBINARS – 8.30-17.30

PROGRAM

WELCOME ADDRESS AND OPENING REMARKS [14.00-14.20]

Authorithies and Giorgio Perilongo.

PART I – THE LEGISLATIVE CONTEXT [14.20 - 15.20]

Chair persons: *Liviana Da Dalt & Roberto Vettor*

The national legislation _ Interviene:

On. Dott.ssa Fabiola Bologna

Member of the Italian Parliament

Member of the Health and Social Commission

Italian Government

Prof.ssa Paola Facchin

Coordination Center and Resister of Rare Diseases

Veneto Region

Pausa 16.00-16.30

The European Context– The ERNs, 4 years after the “kick-off meetings” in Villnius

Interviene: **Martin Dorazil**

Deputy Head of Unit and in charge of the ERNs team in DG Sante

Rare Diseases in the Veneto Region & at the Unviersity Hospital of Padua- Epidemiologic data -

M. Mazzucato, Coordination Center on Rare Diseases, Veneto Region

G. Perilongo, Chairman, Department on Rare Diseases, Univerity Hospital of Padua

PART II RARE DISEASES A FUTURE PARADIGMA – H. 17.30 – 19.00

CAN EVERYBODY HAS THE RIGHT TO BE TREATED? ROUND TABLE DISCUSSION

- **Prof. Rosario Rizzuto**, Rector, University of Padua
- **Prof. Lorenzo Rocco**, Full Professor of Economics, University of Padua
- **Prof. Federico Neresini**, Full Professor of Sociology, Unviersity of Padua
- **Prof. Antonio Da Re**, Full Professor of Philosophy and Bioetics, University of Padua
- **Avv. Fabio Pinelli**, Criminal Lawyer, Forum of Padua, Italy

THURSDAY, FEBRUARY 25TH 2021

FOUR WEBINARS – 8.30-17.30

THE UNIVERSITY HOSPITAL OF PADUA

RARE DISEASE PATIENTS - ORGANISATIONAL MODELS

Webinar 8.30 - 10.00

Introduction – Pietro Maffei

Session I – The hospital “platform” for rare diseases”

Discussants: N. Cazzagon, P. Maffei, F. Rea,

Webinar 10.30 – 12.00

Introduction – Pietro Maffei

Session II -- The transition from the childhood to adulthood

Discussants: R. Colombatti, F. Leon Fascetti, M. Costantini, AM Saieva

Webinar 14.00 – 15.30

Introduction – Pietro Maffei

Session III – Rare Tumors – Similarities and diversities

Discussants: A. Dei Tos, G. Bisogno

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Webinar 16.00 – 17.30

Introduction – Pietro Maffei

Session IV – The hospital network for rare diseases

Discussants: C. Scaroni, P. Gamba, F. Farinati, A. Antonini

FRIDAY, FEBRAURY 26TH 2021
RARE DISEASE DAY - RESEARCH PROJECTS

Department of Medicine

Evento FAD – ECM n. 10.5

WEBINARS 9.30 ALLE 17.30

Programme and registration https://www.rad.unipd.it/FAD_DIMED/login/login.php

Principal investigators: Prof. Roberto Vettor, Prof. Fabrizio Fabris

Scientific Committee: Filippo Ceccato, Sandro Giannini, Franca Anglani, Chiara Giraudo, Diego Cecchin, Francesco Cinetto, Luca Iaccarino, Marco Pizzi, Luca Spiezza, Andrea Visentin, Maria Luigia Randi, Patrizia Pontisso, Pietro Maffei, Matteo Fassan

SATURDAY, FEBRARY 27TH 2021

Hrs.10.30 ALLE 12.00

FAMILY ORGANIZATIONS AND RARE DISEASES – ROUND TABLE DISCUSSION

Introduction : Mario Costantini

Chairperson: Annalisa Scopinaro

Discussants

On. Dott.ssa Fabiola Bologna - On. Dott.ssa Fabiola Bologna

Member of the Italian Parliament

Member of the Health and Social Commission - Italian Government

- ***Dr.ssa Annalisa Scopinaro*** President of the National Federation of Family Associations on Rare Disease
- ***Dr.Loris Brunetta*** Italian Rappresentative of the Family Organization on EuroBloodNet and Eurordis and Member of the Commission on Orphan Drug of EMA
- ***Sig.ra Andreina Comoretto***, Italian Rappresentative of the Family Organizations on ENDOERN