



On the occasion of the
**World Undiagnosed
Disease Day**



UNDIAGNOSED INDIVIDUALS: SHEDDING LIGHT ON THEIR CONDITION

Wednesday, April 30th | 10:45 AM – 1:00 PM
Live streaming on ISS and UNIAMO channels

MODERATOR

Annalisa Scopinaro, President of UNIAMO – Italian Federation for Rare Diseases

10:45

INSTITUTIONAL GREETINGS

Andrea Piccioli, General Director, Istituto Superiore di Sanità (Italian National Institute of Health)

11:00

DEFINING “UNDIAGNOSED INDIVIDUALS”: A LOOK AT NATIONAL ACTIVITIES

Marco Salvatore, Istituto Superiore di Sanità

11:10

THE UNDIAGNOSED DISEASES NETWORK INTERNATIONAL (UDNI)

Domenica Taruscio, UDNI Board Permanent Member

11:20

THE EUROPEAN JOINT ACTION “JARDIN”: ACTIVITIES FOR UNDIAGNOSED INDIVIDUALS

Ursula Unterberger, Medical University of Vienna

11:35

HOW NEW TECHNOLOGIES CAN SUPPORT THE SEARCH FOR A DIAGNOSIS

Emiliano Giardina, Santa Lucia Foundation IRCCS, University of Rome Tor Vergata

11:50

CALLS TO THE RARE DISEASE NATIONAL HELPLINE: THE MAIN ISSUES REPORTED

Marta De Santis, Istituto Superiore di Sanità

12:00

THE SPECIFIC ORPHACODE CLASSIFICATION FOR UNDIAGNOSED INDIVIDUALS

Monica Mazzucato, Veneto Region Coordinating Centre for Rare Diseases

12:15

TELETHON FOUNDATION'S COMMITMENT FOR THE DIAGNOSIS OF GENETIC CONDITIONS

Stefano Benvenuti, Telethon Foundation

12:30

EURORDIS' REQUESTS FOR UNDIAGNOSED INDIVIDUALS

Simona Bellagambi, Vice President of EURORDIS

12:45

DISCUSSION AND CLOSING REMARKS

Annalisa Scopinaro, President of UNIAMO