

Whit Patronage of



From Friday 17th to Sunday 19th April 2026
The Sydney Hotel - Bologna

ACAR's 16th Annual Conference

COLLABORATING TO DRIVE INNOVATION
New Frontiers in Quality Care for Rare Skeletal Diseases

CONFERENCE AGENDA

Friday 17th April

<u>15,00</u>	Arrival and registration of participants
<u>16,00</u>	Welcome tea
<u>16,30</u>	Members' Assembly – Approval of the financial statements
<u>17,00</u>	Opening of the conference and welcome from the Chairperson of ACAR Andrea Romeo
<u>17,45</u>	THE MOVE ALLIANCE – The Multiple Osteochondromas (MO) Voice of Europe Liana la Forgia
<u>18,00</u>	The importance of regional coordination centres for rare diseases Stefano Battistuta, Alessandro Annovazzi and Silvia Forni
<u>18,20</u>	Sustainability of ACAR Alessio Longhi and Manuela Zini
<u>18,45</u>	AssapoRARE: a cooking therapy project Francesca Ravecca
<u>20,00</u>	Dinner
<u>21,30</u>	Evening activities with members

Saturday 18th April

- 9,00 Greetings from the Inter-parliamentary group on Rare Diseases
Maria Elena Boschi *
- 9,05 Greetings from the President of UNIAMO
Annalisa Scopinaro (webcam presentation)

MORNING SESSION

Moderator: **Mauro Celli**

Session dedicated to research

- 9,10 ERN BOND - Rare Disease Patient Journey Study: Why participate in the survey?
Liana la Forgia and **Giuseppina Giordano**
- 9,30 The OLLIER-MAFFUCCI Study: current status
Elena Pedrini and **Diego Martinelli** (webcam presentation)
- 10,00 Palovarotene: a story still to be told
Luca Sangiorgi
- 10,30 Complementary therapies: an innovative approach to ensuring a better quality of life for patients
Armando Magrelli *
- 11,00 Pronti a Salpare – phase 2 study (sailing as a therapeutic intervention on patients living with a rare skeletal disease)
Manila Boarini and **Giuseppina Mariagrazia Farella**
- 11,15 EOS: benefits and limitations in clinical practice
Silvia Ferraro
- 11,30 The MAMBO Study: functional and morphological characterisation of patients with Multiple Osteochondromas
Giulia Rogati and **Vittoria Persi**

Session dedicated to the practical and legal aspects

- 11.45 ANGLAT: Italian National Association for Representation and Protection in the Field of Mobility, Driving and Transport
Claudio Puppo and **Dalila Ranalletta**
- 12.30 Lunch

Parallel sessions on Saturday AssapoRare - A cooking therapy project with Francesca Ravecca

The initiative is sponsored by



AFTERNOON SESSION

Moderator: **Mauro Celli**

14,30 Transitioning from Law 104 to Law 106: key changes and implications
Alessandra Lolli

Session dedicated to collaborations

15,00 "Move4Rare": a successful example of co-creation (RDD 2026)
Andrea Romeo and **Michele Cioffi**

15,20 "InformaRARE Toscana" (a project which aims at favouring connection and collaboration between patient organisations and the Tuscan Local Health Authorities)
Angela Arcuri

15,40 Donald De Sanctis Foundation: "Parliamone New Gen", a therapeutic project of ACAR's younger members
Giulia Guttilla

16,00 Coffee break

Section dedicated to the Open Dialogues – The Third Phase

Moderators: **Luca Sangorgi** and **Silvia Forni**

16,30 ROUND TABLE: Small steps, great hopes: the impact of the Open Dialogues approach on the management of rare skeletal diseases

- **Bambino Gesù Hospital** (V. M. Gonfiantini)
- **Careggi Hospital** (D. A. Campanacci)
- **Gaetano Pini Hospital** (P. Trezza)
- **Gaslini Hospital** (M. B. Michelis and R. Facchi)
- **Gemelli Hospital** (O. Palmacci)
- **Meyer Hospital** (G. Beltrami)
- **Rizzoli Hospital** (A. Rossi) *
- **Umberto I Hospital** (M. Celli)

20,00 Dinner

21,30 Swimming in the open sea – A shared experience
Andrea Romeo and **Fausto Antico**

21,30 **Lunaspina Caruso** (singer) - Live set *

Sunday 19th April

9,00 Arpy and Nave Italia: summer camps for our young members
Matias De La Calle, **Manila Boarini**, **ACAR's New Gen**

12,30 Lunch

* invited to participate in the conference

SPEAKERS

Healthcare Professionals

- **Giovanni Beltrami** – Director of Paediatric Orthopaedics and Traumatology Unit, Paediatric Orthopaedic Oncology Service, and Hand Surgery Service, Meyer University Hospital, Florence, Italy
- **Manila Boarini** – Psychologist, Healthcare researcher, SC Rare Skeletal Diseases, IRCCS Rizzoli Orthopaedic Institute, Bologna, Italy
- **Domenico Andrea Campanacci** – Director of Oncologic and Reconstructive Orthopaedics, Careggi University Hospital, Florence, Italy
- **Mauro Celli** – Director of Congenital Bone Metabolism Diseases, and Head of the Rare Skeletal Dysplasias Centre, Umberto I University Hospital, Rome, Italy
- **Mathias De La Calle** – Psychologist and Psychotherapist, Alma Mater Studiorum, University of Bologna, Italy
- **Roberto Facchi** – Medical Director, Orthopaedics and Traumatology, Lower Limb Deformities Team, Giannina Gaslini Children's Hospital, Genoa, Italy
- **Giuseppina Mariagrazia Farella** – Physical Medicine and Rehabilitation, IRCCS Rizzoli Orthopaedic Institute, Bologna, Italy
- **Silvia Ferraro** – Consultant Radiologist, Diagnostic and Interventional Radiology, IRCCS Rizzoli Orthopaedic Institute, Bologna, Italy
- **Giuseppina Giordano** – ERN BOND Coordination Team, IRCCS Rizzoli Orthopaedic Institute, Bologna, Italy
- **Michaela Veronika Gonfiantini** – Consultant in Medical Genetics at the Rare Disease and Medical Genetics Unit, Bambino Gesù Children's Hospital, Rome, Italy
- **Diego Martinelli** – Head of the Inpatient Metabolic Diseases, Bambino Gesù Children's Hospital, Rome, Italy
- **Maria Beatrice Michelis** – Consultant Orthopaedic and Trauma Surgeon, Orthopaedics and Traumatology Unit, Giannina Gaslini Children's Hospital, Genoa, Italy
- **Oswaldo Palmacci** – Consultant Orthopaedic Surgeon, Unit of Orthopaedics and Traumatology, Agostino Gemelli University Hospital Foundation, Rome, Italy
- **Elena Pedrini** – Research Biologist, Rare Skeletal Diseases Unit, SC Rare Skeletal Diseases, IRCCS Rizzoli Orthopaedic Institute, Bologna, Italy
- **Vittoria Persi** – Student, IRCCS Rizzoli Orthopaedic Institute, Bologna, Italy
- **Giulia Rogati** – Healthcare Researcher at the Movement Analysis Lab, IRCCS Rizzoli Orthopaedic Institute, Bologna, Italy
- **Andrea Rossi** – Director, IRCCS Rizzoli Orthopaedic Institute, Bologna, Italy
- **Luca Sangiorgi** – Head of SC Rare Bone Diseases Department, IRCCS Rizzoli Orthopaedic Institute, Bologna, Italy, Coordinator of the European Reference Network for Rare Bone Diseases ERN BOND
- **Paolo Trezza** – Medical Director, Traumatology and Orthopaedic Oncology, Gaetano Pini-CTO Orthopaedic and Traumatology Specialist Centre (ASST), Milan, Italy

Institutional Representatives

- **Angela Arcuri** – President of Forum Toscano Malattie Rare
- **Maria Elena Boschi** – President of the Inter-parliamentary Group on Rare Diseases
- **Armando Magrelli** – International Relations Office Manager at AIFA
- **Annalisa Scopinaro** – President of UNIAMO

Other professionals

- **Fausto Antico** – Swim coach and coordinator for NAL
- **Michele Cioffi** – National Point of Contact for ASI Cultura
- **Alessandra Lolli** – National Legal Expert in Disability Law
- **Claudio Puppo** – National Chairperson of ANGLAT
- **Dalila Ranaletta** – Member of the ANGLAT Scientific Committee

Members of ACAR

- **Alessandro Annovazzi** – Member and Regional Contact for the Lazio Region
- **Stefano Battistuta** – Member and Regional Contact for the FVG Region
- **Silvia Forni** – Member Scientific Board
- **Giulia Guttilla** – Trustee
- **Liana la Forgia** – ERN BOND ePAG, and International Relations Manager
- **Alessio Longhi** – Trustee
- **Francesca Ravecca** – Member
- **Andrea Romeo** – Chairperson of ACAR
- **Manuela Zini** – Treasurer