

From Friday 11th to Sunday 13th April 2025
HOTEL AMBASCIATORI – RIMINI



15th ACAR CONFERENCE

FROM UNMET NEEDS TO SHARED
SOLUTIONS

*New insights in the management of patients with
Multiple Osteochondromas and Enchondromatosis*

AGENDA

Friday 11th April

<u>15,00</u>	Arrival and registration
<u>16,00</u>	Welcome and afternoon tea
<u>16,30</u>	Assembly of members and approval of annual financial statement
<u>16,45</u>	Greetings from the Chair of ACAR and opening of the conference Andrea Romeo
<u>17,00</u>	EURORDIS Partnership - The impact of rare genetic diseases on mental health Andrea Romeo and Liana la Forgia
<u>17,15</u>	Update on current activities being undertaken by ACAR Eleonora Grippa
<u>17,30</u>	A Room For Yourself – Counselling and psychological support service Claudia Monti
<u>17,45</u>	The importance of communication for Patient Associations Rosaria Vincelli
<u>18,00</u>	Every little helps: the importance of volunteering, fundraising and donating 0.5% of income tax Giulia Guttilla, Lorenzo Profico and Manuela Zini <i>ACAR's volunteers sharing their experience</i>
<u>19,30</u>	Dinner

Parallel sessions:

- Meeting of European Rare Bone Disease Patient Organisations (Multiple Osteochondromas and Enchondromatosis)
- A Room For Yourself - counselling and psychological support service
- We are not islands, we are an archipelago – welcoming service for new members

21,30

ACAR - THE NEW GENERATION

- How I see disability – Chiara Racanelli's personal reflections on disability
- RottAmiamoci - the success story of a sailing experience

Saturday 12th April

9,00

Greetings from the Minister for Disabilities
Alessandra Locatelli * (video message)

9,10

Greetings from the Chair of UNIAMO (Italian patient-driven Federation of rare disease Patient Associations)
Annalisa Scopinaro (live online presentation)

SESSION I

Moderators: **Mauro Celli** and **Federico Canavese**

9,15

The importance of European Patient Advocacy Groups (ePAGs) for the European Reference Network ERN BOND
Luca Sangiorgi and **Liana la Forgia**

9,30

From initial research to clinical trials: the rollercoaster course of a new drug creation
Maurizio Pacifici

9,50

The diagnosis of Enchondromatosis: it remains a current challenge
Nara Sobreira (live online presentation)

10,10

Pain and fatigue in patients living with Multiple Osteochondromas and Ollier Disease: what we know and what we could do
Ariane Kwiet and **Trine Bathen**

10,40

Treatment of patients with Multiple Osteochondromas: clinical and surgical cases
Jens Eckhoff

11,00

Three lectures

- Management of Multiple Osteochondromas on upper limb
- Management of Multiple Osteochondromas on lower limb
- Lengthening and correction of deformities in relation to Ollier Disease

Dror Paley

12,30

Lunch

SESSION II

Moderator: **Leonardo D'Agruma**

<u>14,30</u>	Biobank and Registry, state of the art and current studies Marina Mordenti and Manuela Locatelli
<u>15,00</u>	The study on Ollier-Maffucci: a successful example of multistakeholder collaboration Gabriella Massa, Davide Scognamiglio, Carlo Dionisi Vici (live online presentation)
<u>15,30</u>	A four-year experience of outdoor camps Ready to sail - the experience of a gamification method Manila Boarini
<u>16,00</u>	Coffee break
<u>16,30</u>	ROUNDTABLE - THE OPEN DIALOGUE APPROACH Care management of patients during the transition from paediatric to adult healthcare from unmet needs to shared solutions Moderators: Silvia Forni and Luca Sangiorgi <ul style="list-style-type: none">• Oswaldo Palmacci• Maria Beatrice Michelis• Annarita Ronchetti• Michaela Veronika Gonfiantini• Paolo Trezza• Manila Boarini• Marina Mordenti
<u>17,30</u>	Questions and answers for the Roundtable and selection of potential solutions Plenary session Conclusions Luca Sangiorgi
<u>19,30</u>	Dinner
<u>21,30</u>	ROAR! A digital story of fossils and dinosaurs Davide Scognamiglio

Saturday morning and afternoon

MakeUp&Smile – A make-up session for children and teenagers

Anna Stango

Sunday 13th April

<u>9,00</u>	MakeUp&Smile – session for adults (by appointment) Anna Stango
<u>10,30</u>	Disability reform: the medical certificate for the National Institute for Social Security Laura Andrao (live online presentation)
<u>11,00</u>	I and Us – self-analysis and relationship experiences Manila Boarini
<u>12,30</u>	Conclusions
<u>13,00</u>	Lunch

The UCIPeM Family Counselling Centre in Faenza offers counselling and psychological support to those who request the service during the three-day conference

* *Invited to participate*

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Federazione Italiana Malattie Rare



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Patronage to the Ministry of Health requested

INFO



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www.acar-aps.org

SPEAKERS

- **Trine Bathen** - Occupational Therapist, TRS National Resource Centre for Rare Disorders, Sunnaas Rehabilitation Hospital, Norway
- **Manila Boarini** - Psychologist, SC Rare Skeletal Diseases, IRCCS Istituto Ortopedico Rizzoli, Bologna, Italy
- **Federico Canavese** - Director of the Department of UOC Orthopaedic and Traumatology, IRCCS Giannina Gaslini, Genoa, Italy and Lecturer at the Università degli Studi di Genova, DISC Department of Surgical Sciences and Integrated Diagnostics, Genoa, Italy
- **Mauro Celli** - Paediatrician, Head of Center for Rare Skeletal Dysplasia, Policlinico Umberto I, Rome, Italy
- **Leonardo D'Agruma** - Biologist, Geneticist at UOC Medical Genetics, Casa Sollievo della Sofferenza, San Giovanni Rotondo, Italy
- **Jens Eckhoff** - Paediatric Orthopaedic Surgeon, BG Unfallklinik Murnau, Germany
- **Michaela Veronika Gonfiantini** - Medical Director of Skeletal Dysplasia UOC Rare Disease and Medical Genetics Unit, Ospedale Pediatrico Bambino Gesù, Rome, Italy
- **Ariane Kwiet** - Specialist in Physical Medicine and Rehabilitation, TRS National Resource Centre for Rare Disorders, Sunnaas Rehabilitation Hospital, Norway
- **Maria Beatrice Michelis** - Orthopaedist, Medical Director, IRCCS Ospedale Gaslini, Genoa, Italy
- **Marina Mordenti** - Representative for the Disease Registry, SC Rare Skeletal Diseases, IRCCS Istituto Ortopedico Rizzoli, Bologna, Italy
- **Manuela Locatelli** - Representative for the Genetic Biobank BIOGEN, SC Rare Skeletal Diseases, IRCCS Istituto Ortopedico Rizzoli, Bologna, Italy
- **Maurizio Pacifici** - Director of Orthopaedic Research, Children' s Hospital of Philadelphia, USA
- **Dror Paley** - Orthopaedic Surgeon, Paley Orthopaedic & Spine Institute, West Palm Beach, Florida
- **Oswaldo Palmacci** - Medical Surgeon, Medical Director at UOC Orthopaedics and Traumatology, Policlinico Universitario Fondazione Agostino Gemelli, Rome, Italy
- **Anna Bruna Ronchetti** - Medical Director of Physical Medicine and Rehabilitation, IRCCS Giannina Gaslini, Genoa, Italy
- **Luca Sangiorgi** - Head of SC Rare Bone Diseases Department, IRCCS Istituto Ortopedico Rizzoli, Bologna, Italy and Coordinator of the European Reference Network for Rare Bone Diseases ERN BOND, IRCCS Istituto Ortopedico Rizzoli, Bologna, Italy
- **Davide Scognamiglio** - Bioinformatician, SC Rare Diseases Department, IRCCS Istituto Ortopedico Rizzoli, Bologna, Italy
- **Nara Sobreira** - Researcher, Johns Hopkins University, Baltimore, USA
- **Paolo Trezza** - Medical Director of Orthopaedics, Traumatology and Oncology, ASST Centro Specialistico Ortopedico Traumatologico Gaetano Pini, Milan, Italy
- **Carlo Dionisi Vici** - Head of UOC Division of Metabolic and Hepatic Diseases, Ospedale Pediatrico Bambino Gesù IRCCS, Rome, Italy



Associazione Conto alla Rovescia
per Malattia Esostosante, Malattia
di Ollier e Sindrome di Maffucci

INSTITUTIONS

- **Alessandra Locatelli** - Minister for Disabilities
- **Annalisa Scopinaro** - Chair of UNIAMO (Italian patient-driven Federation of rare disease Patient Associations)

OTHER SPEAKERS

- **Laura Andrao** - Lawyer specialised in national disability law
- **Claudia Monti** - Counselling and psychological support service, UCIPEM Faenza
- **Lorenzo Profico** - Fundraising and subsidised finance planner
- **Anna Stango** - Beauty consultant
- **Rosaria Vincelli** - Corporate communication consultant

ACAR'S MEMBERS

- **Silvia Forni** - Scientific Board
- **Eleonora Grippa** - Scientific Board
- **Giulia Guttilla** - Trustee
- **Liana la Forgia** - ERN BOND ePAG, and ACAR's International Communications
- **Gabriella Massa** - Vice Chair
- **Chiara Racanelli** - Member
- **Andrea Romeo** - Chair
- **Manuela Zini** - Treasurer

Many thanks to Claudia Feliciani, Maria Roncaccia and Giuseppe Scognamiglio for assisting with organising the conference.

