

Friday 12th to Sunday 14th April 2024
The Sydney Hotel - Bologna

ACAR's 14th Annual Conference

**TRANSVERSAL COLLABORATION TO SUPPORT RESEARCH
AND IMPROVE THE QUALITY OF LIFE OF PATIENTS WITH
RARE GENETIC DISEASES**

AGENDA

Friday 12th April

3:00 pm *Arrival and registration*

4:00 pm *Welcoming afternoon tea*

4:30 pm *Assembly of members and approval of annual financial statement*

4:45 pm *Opening of the conference*
Andrea Romeo, ACAR Chair

5:00 pm *pm Presentation of ACAR's activities undertaken in 2023, as well as activities planned for the current year*
Eleonora Grippa, ACAR member

5:15 pm *Presentation of the welcoming service for new members called "We are not an island, we are an archipelago"*
Maria Roncaccia and **Francesca Ravecca**, ACAR members

5:25 pm *Presentation of the service "A Room to Yourself" Counselling service and psychological support in collaboration with the Consultorio Familiare UCIPEM (Family Counselling Centre) of Bologna*
Emanuela Elmo - Chair of the Counselling Services for Family Liasons of the APS Consultorio UCIPEM

5:35 pm *The potentials of an individual lifelong plan for patients and its application (ex L. 328/2000)*
Laura Andrao, Solicitor with expertise in the national law on disability

Parallel Session from 5.30 pm

- First Meeting of the EUROPEAN RARE BONE DISEASE ALLIANCE with a number of European Patient Associations
- "We are not an island, we are an archipelago" and a "Room for yourself" services

[6:05 pm](#) Presentation of fundraising activities
Alessio Longhi, ACAR member

[7:30 pm](#) Dinner

[9:30 pm](#) Viewing of the short-film called “Vela D’Amare (Love for Sailing)”, directed by Davide Scognamiglio, which has been awarded the Uno Sguardo Raro UNIAMO 2023 award

Saturday 13th April **Morning Session**

Moderator **Luca Sangiorgi**

[9:00 am](#) Greetings from the Minister for disability
Alessandra Locatelli, (message)

[9:10 am](#) Greetings from the representative of the Coordination Centre of Rare Diseases of the Emilia-Romagna region
Elisa Rozzi

[9:15 am](#) Greetings from the Chair of UNIAMO (Italian patient-driven Federation of Rare Disease Patient Organisations)
Annalisa Scopinaro (video message)

[9:20 am](#) The value of ERN BOND, the European Reference Network for rare bone disease patients
Luca Sangiorgi, ERN BOND Network Coordinator and Head of SC Rare Skeletal Diseases, IOR, Bologna
Liana la Forgia, ERN BOND ePAG and ACAR member

[9:35 am](#) Update on development of pharmaceutical treatment for Multiple Osteochondromas
Maurizio Pacifici, Director of Research, Children’s Hospital of Philadelphia

[10:20 am](#) Update on scientific evidence on Ollier Disease and Maffucci Syndrome
Nara Sobreira, Researcher, Institute of Genetics Medicine, John Hopkins University of Baltimore (presentation in English)

[11:05 am](#) Treatment of MO in Germany: past, present and future
Jens Eckhoff, Specialist in orthopaedics and traumatology, BG Unfallklinik Murnau, Germany (presentation in English)

[11:25 am](#) The role of occupational therapy in patients with Multiple Osteochondromas and Ollier Disease – A Norwegian perspective
Trine Bathen, Occupational therapist, TRS National Resource Centre for Rare Disorders, Norway (presentation in English)

[11:45 am](#) Preliminary results on two Norwegian projects including Multiple Osteochondromas and Ollier Disease patients
Ariane Kwiet, Medical Doctor, TRS National Resource Centre for Rare Disorders, Norway (presentation in English)

[12:05 pm](#) Occupational therapy in Italy
Elena Merighi, Occupational Therapist, Modena Polyclinic

[1:00 pm](#) Lunch

Afternoon Session

Moderator **Luca Sangiorgi**

[2:30 pm](#) The Value of sharing: the experience of mutual support groups for siblings
Giulio Iraci, Representative of the Comitato Sibling Onlus

[3:30 pm](#) Management of patients with Multiple Osteochondromas, Ollier Disease and Maffucci Syndrome explained through the experience of a number of different Italian hospitals

- University Hospital, IRCCS Anna Mayer, Florence

Giovanni Beltrami, Medical Director of Paediatric Orthopaedics and Traumatology SOC Department and of the Paediatric Orthopaedics Oncology

- Careggi University Hospital, Florence

Domenico Andrea Campanacci, Medical Director of SODc Oncological and Reconstructive Orthopaedics

- SC Paediatric Orthopaedics and Traumatology, IOR, Bologna

Luigi Di Gennaro, Medical Director of Paediatric Orthopaedics and Traumatology

- AORN Santobono, Naples

Gian Luigi Federico, Medical Director of Orthopaedics and Traumatology

- ASST Orthopaedic and Traumatology Centre Gaetano Pini, Milan

Antonio Memeo, Director of Paediatric Orthopaedics and Traumatology U.O.

Paolo Trezza, Medical Director of Oncological Orthopaedics and Traumatology

- Giannina Gaslini Hospital, Genoa

Maria Beatrice Michelis, Orthopaedist, Medical Director

- Umberto I University Hospital, Rome

Carmine Zoccali, Surgeon specialising in Orthopaedics and Traumatology

- Question & Answer session

[5:35 pm](#) Bone infections resulting from orthopaedic surgery
Carlo Salomone, Head of the S.S.D. Orthopaedics Septic Surgery,
Ospedale S.M. Misericordia, Albenga

[6:00 pm](#) Access to medically assisted procreation (PMA) and
preimplantation genetic diagnosis (PGD or PGT): the experience of
the AUSL in Ferrara
Andrea Gallinelli, Head of Physiopathology for Human Reproduction
and PMA, Ospedale del Delta, Ferrara

[6:30 pm](#) Presentation of the results of the Open Dialogues activity
carried out in 2023 and future challenges
Luca Sangiorgi, Head of SC Rare Skeletal Diseases, IOR, Bologna
Davide Scognamiglio, Bioinformatician, SC Rare Skeletal Diseases,
IOR, Bologna
Silvia Forni, ACAR member

[7:30 pm](#) Dinner

Sunday 14th April

[10:00 am](#) The impact of the emotional experiences on patients and
the interactions of patients with others
Manila Boarini, Psychologist, SC Rare Skeletal Diseases, IOR, Bologna

[11:00 am](#) Outdoor activities: "Tender To Nave Italia Foundation:
pre-embarkation and post-embarkation information", and "Arpy, the
high-altitude adventure"

[12:00 am](#) Conclusions

[1:00 pm](#) Lunch

The UCIPeM Family Counselling Centre in Bologna will offer
counselling and psychological support to those who will request the
service during the three day conference

INFO:



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www.acar-aps.org