

A.C.A.R. APS CONFERENCE

Working towards a multidisciplinary and shared approach of rare disease patients transition from paediatric to adult care management

14 - 15 - 16 April 2023
Grand Hotel Continental Tirrenia - Pisa

PROGRAMME

Friday 14th April

<u>3:00 pm</u>	Welcoming of current and new members
<u>4:00 pm</u>	Afternoon tea
<u>5:00 pm</u>	Members assembly and approval of annual financial statement
<u>5:15 pm</u>	Opening of the conference and presentation of A.C.A.R.'s activities undertaken over the last year Gabriella Massa - A.C.A.R. Aps Chair
<u>5:30 pm</u>	Current projects and activities related to Multiple Osteochondromas, Ollier disease and Maffucci syndrome Eleonora Grippa - A.C.A.R. Aps Project Manager of the scientific board for Multiple Osteochondromas Davide Scognamiglio - A.C.A.R. Aps Project Manager of the scientific board for Ollier disease and Maffucci syndrome
<u>6:00 pm</u>	The significance of the UNIAMO membership (UNIAMO is the Italian Federation of rare disease Patient Associations) Luisa Testa - A.C.A.R. Aps member Andrea Orilio - A.C.A.R. Aps member
<u>6:30 pm</u>	"A Room for Yourself" Counselling service and psychological support in collaboration with Consultorio familiare UCIPEM of Pisa Andrea Romeo - A.C.A.R. Aps Vice-Chair

<u>7:00 pm</u>	The success of the story of “The Star-Nosed Mole” since its publication last year. A book written to highlight the importance of inclusion and diversity Veronica Morselli - A.C.A.R. Aps member
<u>7:30 pm</u>	Plastic recycling workshop How to make a tortoise to take on board Nave Italia (a sailing ship on which are carried out educational and inclusive projects) Katrin Grote-Baker - A.C.A.R. Aps member
<u>8:00 pm</u>	Dinner
<u>9:00 pm</u>	Preparation for the working group session scheduled for Saturday afternoon

Saturday 15th April

MORNING SESSION - Sala Ferretti

Moderator: **Leonardo D'Agruma** – Biologist, UOC Genetica Medica CSS, San Giovanni Rotondo

<u>9:00 am</u>	Introduction and welcoming of members and speakers
<u>9:10 am</u>	Greetings from the Chair of UNIAMO Annalisa Scopinaro
<u>9:20 am</u>	Future research prospects of Multiple Osteochondromas and the development of potential treatments Maurizio Pacifici - Director of Research, Children's Hospital of Philadelphia
<u>10:20 am</u>	State of the art and latest scientific discoveries in regards to Ollier disease and Maffucci syndrome Nara Sobreira - Researcher, Institute of Genetics Medicine, John Hopkins University of Baltimore

- 11:20 am Norwegian projects on pain and fatigue in patients with Multiple Osteochondromas and Ollier disease
Ariane Kwiet - Specialist in physical medicine and rehabilitation TRS National Resource Centre for Rare Disorders
- 11:40 am Bionbank and registry, latest news on genetic research from the IOR
Marina Mordenti - Researcher, SC Rare Skeletal Diseases, IOR, Bologna
- 12:10 pm Experience with treating Multiple Osteochondromas, Ollier disease and Maffucci syndrome at the Santo-bono Hospital of Naples
Gian Luigi Federico - Medical Director, UOC Ortopedia e Traumatologia Santobono, Naples
Emiliana Matania - Anaesthesist, Medical Director, Santobono, Naples
- 12:35 pm Updates on the uses of EOS in the follow-up of patients with Multiple Osteochondromas, Ollier disease and Maffucci syndrome patients
Giovanni Gallone - Medical Director, SC Ortopedia e Traumatologia Pediatrica, IOR, Bologna
- 1:10 pm Lunch

AFTERNOON SESSION - Sala Ferretti

- 3:00 pm Definition of priority pathways of care for Multiple Osteochondromas, Ollier disease and Maffucci syndrome patients during the transition from paediatric to adult care management
- Open dialogue
- Introduced by **Alessandro Sergi** - Manager, Azienda USL Toscana Centro

3:15 pm Working groups

5:00 pm End of working groups

Luca Sangiorgi - Head of SC Rare Skeletal Diseases,
IOR, Bologna, ERN BOND Italia Network Coordinator

5:15 pm The value of Patients Associations according to
SITOP (the Italian Society of Paediatric Orthopaedics
and Traumatology)

Giovanni Beltrami - Director of the Department of
SOC Paediatric Orthopaedics and Traumatology,
SOS Hand Surgery, AOU Meyer, Florence

5:45 pm "Terapia dell'Avventura", a collaboration of the
Marina Militare and the Fondazione Nave Italia

Paolo Cornaglia Ferraris - Scientific director of
Fondazione Tender To Nave Italia

Pierpaolo Ribuffo - Admiral Marina Militare and
Vice-Chair of Fondazione Tender To Nave Italia

6:30 pm Sporting activities beyond limitations

Manila Boarini - Psychologist, SC Rare Skeletal
Diseases, IOR, Bologna

Giuseppe Scognamiglio - A.C.A.R. Aps Trustee

Guest speaker: **Francesco Bocciardo** - Paralympic
gold medalist

**Manila Boarini will run sessions for children and teenagers
during the conference which will take place in Room 3**

8:00 pm Dinner

Sunday 16th April

- 10:00 am “I and us” – The impact of patient inner experiences and relationships with others
Manila Boarini - Psychologist SC Rare Skeletal Diseases, IOR, Bologna
- 11:00 am General information on the activities to be undertaken on Nave Italia and the Arpy summer camp
- 12:00 pm End of session
- 1:00 pm Lunch
- 3:00 pm Farewell

The Consultorio Familiare UCIPeM di Pisa will offer counselling service and psychological support over the three days to those who will require the service.

Per info:



info@acar-aps.org



www.acar-aps.org

Healthcare professionals taking part in the open discussion scheduled for Saturday at 3 pm:

Dr Maria Francesca Bedeschi Geneticist UOSD Medical

Genetics - Ospedale Maggiore Policlinico, Milano

Dr Giovanni Beltrami Director of the Department of SOC Paediatric Orthopaedics and Traumatology, SOS Paediatric Oncological Orthopaedics, SOS Hand Surgery - AOU Meyer Firenze

Dr Camilla Caldarini Medical Director of Paediatric Orthopaedics - ASST Gaetano Pini-CTO, Milano

Prof Domenico Campanacci Director of the Department of SODC Orthopaedic Oncology and Reconstructive Surgery - AOU Careggi, Firenze

Dr Nunzio Catena Head of UOSD Center for Reconstructive Surgery of the Hand - Ospedale Gaslini, Genova

Dr Mauro Celli Pediatrician, Head of Center for Rare Skeletal Dysplasia - Policlinico Umberto I, Roma

Dr Marta Cervo UO Functional Rehabilitation - AUO Meyer, Firenze

Dr Leonardo D'Agruma Biologist Geneticist UOC Medical Genetics - Casa Sollievo della Sofferenza San Giovanni Rotondo

Dr Gian Luigi Federico Medical Director of UOC Orthopaedics and Traumatology - AORN Santobono Napoli

Dr Giovanni Gallone Medical Director of SC Paediatric Orthopaedics and Traumatology - Istituto Ortopedico Rizzoli, Bologna

Dr Ariane Kwiet Specialist in Physical Medicine and Rehabilitation - TRS National Resource Centre for Rare Disorders, Sunnaas Rehabilitation Hospital, Norway

Dr Laura Masi Director of the Department of Bone and Mineral Metabolism Disorders - AOU Careggi, Firenze

Dr Emiliana Matania Anesthetist, Medical Director - AORN Santobono Napoli

Dr Maria Beatrice Michelis Orthopaedist, Medical Director -
Ospedale Gaslini Genova

Dr Marina Mordenti Researcher SC Rare Skeletal Diseases -
Istituto Ortopedico Rizzoli, Bologna

Prof Maurizio Pacifici Researcher - Children' s Hospital of
Philadelphia

Dr Elisabetta Pelo Director of the Genetic Testing
Department - AOU Careggi, Firenze

Dr Luca Sangiorgi Geneticist - Head of SC Rare Diseases
Department - Istituto Ortopedico Rizzoli, Bologna

Dr Carmela Schiavone Psychotherapist - As.It.O.I.

Prof Nara Sobreira Researcher - Johns Hopkins University
Baltimore

