

❖ **SCIENTIFIC ADMINISTRATION**  
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❖ **LIST OF SPEAKERS AND MEMBERSHIP**

Giovanna Mantovani, University of Milan, I  
Mara Riminucci, University of Rome “La Sapienza”, I  
Yingtzi Yang, Harvard Dental School, Boston, MA, USA  
Ed Hsiao, UCSF, San Francisco, USA  
Luisa de Sanctis, University of Turin, I  
Daniele Tessaris, University of Turin, I  
Malgorzata Wasniewska, University of Messina, I  
Roland Chapurlat, University of Lyon, F  
Natasha M Appelman-Dijkstra, Leiden University, NL  
Michael Collins, NIH NIDCR Bethesda, USA  
Rodolfo Capanna, University of Pisa, I  
Pablo Florenzano, Catholic University of Santiago, Chile  
Alison Boyce, NIH NIDCR Bethesda, USA  
Lorenzo Genitori, AOU Meyer, Florence, I  
Giuseppe Spinelli, AOU of Careggi, Florence, I  
Robert Stanton, Nemours Children Hospital, Orlando, USA  
Giovanni Beltrami, AOU of Careggi, Florence, I  
Ernesto Ippolito, University of Rome Tor Vergata, I  
Maria Luisa Brandi, University of Florence, I  
Anne Marie Heegaard, University of Copenhagen, DK  
Diego Fornasari, University of Milan, I  
Renato Vellucci, AOU Careggi, Florence, I  
Aris Economides, VP of Research at Regeneron Pharmaceuticals Inc, USA  
Laura Masi, AOU of Careggi, Florence, I  
Neveen Hamdy, Leiden University, NL  
Kassim Javaid, University of Oxford, GB  
Luca Sangiorgi, Bologna, I  
Valter Dal Pos, Eamas, Torino, I



❖ **ORGANIZATION ADMINISTRATION (Professionals):** EXPOS srl, Via Ragazzi del 99, 51. 50141 Firenze - Tel. +39 055 2336663

❖ **ORGANIZATION ADMINISTRATION (Patients and families):**  
EAMAS Association, Via Borgovecchio 25, 10041 Carignano (TO),  
Cell. +39 340 3792849, [dalpos@eamas.net](mailto:dalpos@eamas.net)

EAMAS headquarter : Via Borgovecchio 25,  
10041 Carignano (TO) Italy, [www.eamas.net](http://www.eamas.net)  
Donations: Bank acc. IT65T0103001000000003440054  
Dona il 5 per mille C.F. 94037550012

For information and events' reservation (evening hours):  
Valter Dal Pos – Eamas Association +39 340 3792849  
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Eamas is a non-profit patient's association, operating since 1998, enhancing and promoting the relationships between researchers, doctors, specialists, patients and families. We aim to improve the assistance to patients, and their families, having rare diseases. We were born from the need to address, support and be accountable when holding a rare condition. A disease is defined rare when occurs in five people every 10,000 inhabitants. Millions of people in Italy, tens of millions in Europe and worldwide are involved by rare conditions. We believe that the experience of those who suffer and those who help should be further enhanced to promote education and care. We aim to promote research and rise resources in order to improve the quality of life of patients and their families. Eamas is in collaboration with other Italian, European and world wide patient's groups sharing the interest to develop basic research, new drugs discovery, new therapies, aimed to improve care and support for people having rare conditions. Our goal is to disseminate a culture of aggregation between all players and stake holders in order to sponsor adequate answers that rare conditions still require.

WITH THE SUPPORT OF:



\*This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 847078\*

We thank all those who gave and make their own contribution to the realization of the event.

## Fibrous dysplasia Mc Cune-Albright Syndrome

# 4<sup>th</sup> Meeting of the International FD-MAS Consortium and 8<sup>th</sup> Eamas Conference

28 ÷ 30 May 2019

Albani Hotel (28<sup>th</sup> – 29<sup>th</sup> May)  
Via Fiume, 12  
Florence – Italy

Circolo Unificato (30<sup>th</sup> May)  
Via della Scala, 68  
Florence – Italy

### Live Streaming

Facebook “EAMAS Stop Rare Diseases”  
Youtube “EAMASandYOU”

ECM, 11 credits



8.00 Registration

8.30 Opening and Welcome

❖ **FIRST SESSION: BASIC RESEARCH**

Chairmen: Michael Collins and Luca Sangiorgi

08.45 GNAS Spectrum of Disorders

Giovanna Mantovani, University of Milan, I

09.05 The Role of Stem Cells in FD Initiation and Maintenance

Mara Riminucci, University of Rome "La Sapienza", I

09.25 Mouse models of FD/MAS

Yingzi Yang, Harvard Dental School, Boston, MA, USA

09.45 Human Cellular Models of FD/MAS

Ed Hsiao, UCSF, San Francisco, USA

10.15 Gene Mutation Analysis in FD/MAS

Luisa de Sanctis, University of Turin. I

10.25 Future Agenda of Basic Research

Panel Discussion

10.45 Coffee Break

❖ **SECOND SESSION: EXTRASKELETAL DISEASE**

Chairmen: Daniele Tassarìs and Neeven Hamdy

11.00 Endocrine Disease in MAS

Daniele Tassarìs University of Turin, I

11.20 Gonadal Disease in MAS

Malgorzata Wasniewska, University of Messina, I

11.40 The Role of Inflammation in FD/MAS

Roland Chapurlat, University of Lyon, F

12.00 Cancer Risk in FD/MAS

Natasha M Appelman-Dijkstra Leiden University, NL

12.20 MAS – Associated Gastrointestinal Pathologies

Michael Collins, NIH NIDCR Bethesda, USA

12:40 Lunch and Poster Session

❖ **THIRD SESSION: INSIGHT IN DIAGNOSIS**

Chairmen: Natasha M Appelman-Dijkstra

14.00 Fibrous Dysplasia Imitating Malignancy

Rodolfo Capanna, University of Pisa, I

14.20 Use of Biological Markers in FD/MAS

Pablo Florenzano, Catholic University of Santiago, Chile

14.40 Imaging Modalities in FD/MAS

Alison Boyce, NIH NIDCR Bethesda, USA

15.00 Coffee Break

❖ **FORTH SESSION: SURGICAL THERAPY**

Chairmen: Giovanni Beltrami and Lorenzo Genitori

15.15 Craniofacial Fibrous Dysplasia: The Point of View of the Neurosurgeon

Lorenzo Genitori, AOU Meyer, Florence, I

15.35 Craniofacial Fibrous Dysplasia: The Point of View of the Maxillofacial Surgeon

Giuseppe Spinelli, AOU of Careggi, Florence, I

15.55 Scoliosis in FD/MAS

Robert Stanton, Nemours Ch, Orlando, USA

16.15 The Expert Orthopaedic Surgeon

Giovanni Beltrami, AOU of Careggi, Florence, I

16.35 Surgical Treatment of Bone Lesions In Mc Cune Albright Syndrome. A twenty years experience.

Ernesto Ippolito, University of Rome Tor Vergata, I

16.55 Presentation from the winner of the Charles Harles Award for Excellence in FD/MAS Research

17.10 FD/MAS International Consortium Terms of Reference

Wednesday May 29

❖ **FIFTH SESSION: THE PAIN ISSUE**

Chairman: Maria Luisa Brandi and Anne Marie Heegaard

08.30 Pathogenetic Mechanisms of Bone Pain

Diego Fornasari, University of Milan, I

08.50 Clinical Evaluation of Bone Pain

Renato Vellucci, AOU Careggi, Florence, I

09.10 What Are We Doing to Answer Patients' Needs?

Roland Chapurlat, University of Lyon

09.30 Designing Analgesic Trials

Panel Discussion

10.10 Coffee Break

❖ **SIXTH SESSION: PHARMACOLOGICAL THERAPY**

Chairmen: Alison Boyce and Aris Economides

10.30 FD/MAS: Treating Children and Adolescents with Antiresorptive medications

Alison Boyce, NIH NIDCR Bethesda, USA

10.50 Results from Recent Clinical Trials

Roland Chapurlat, University of Lyon, F

11.10 Osteoporosis Treatment in Special Patients Population

Laura Masi, AOU of Careggi, Florence, I

11.30 Denosumab Trials

Neeven Hamdy, Leiden University, NL

11.50 Prospects for the Future

Panel Discussion

❖ **SEVENTH SESSION: QUALITY OF LIFE ANALYSIS**

Chairmen: Kassim Javaid and Pablo Florenzano

12.30 Bond a Platform for Rare Bone Disorders

Luca Sangiorgi, Bologna, I

12.50 Driving Improvement in Clinical Centres – Effectiveness, Efficiency and Patient Experience – Designing a Global Audit of clinical Services Based on the Global Pathway

Valter Dal Pos, Eamas, Torino, I

13.10 Bringing Together Research Across Borders: Natural History of Disease Database opportunities in the ERN and further Afield

Michael Collins, NIH NIDCR Bethesda, USA

13.30 Lunch and Poster Session

13.30 End session ECM

Wednesday May 29 (afternoon)

Session organized by EAMAS

14.30 **INDIVIDUAL MEETINGS WITH SPECIALISTS (\*)**

Meetings' schedule and allowed participants will be organized by Eamas and in following of a written and mandatory request to be sent to Eamas at [info@eamas.net](mailto:info@eamas.net)

19.00 End of the 4th Meeting of the International FD-MAS Consortium

Thursday May 30

8<sup>th</sup> EAMAS Conference

Venue: Circolo Unificato, Via della Scala, 68, Florence

09.30 - 11.00 8<sup>th</sup> Eamas Conference

11.00 – 12.30 International Patient's and Association's Forum

13.00 Lunch, end of the event and farewell

The program of May 30<sup>th</sup> is in preparation and it will depend upon the number of participants that will express their intention to Eamas. Topics that will concern the collaboration and development of the network of associations and common interests, at the global level, will be discussed.

**INFORMATION FOR PATIENTS and FAMILIES**

**(\*) INDIVIDUAL MEETINGS WITH SPECIALISTS**

A special attention must be applied for the organization of the individual meetings with specialists. The request to meet specialists must be sent to Eamas along with the confirmation of the participation at the event together with a brief explanation of the topics to be discussed. The families have to prepare, at their own care, the patient's file that should be organized at the best, with the most recent information in evidence, in order to minimize the evaluation time and facilitate readings. Thanks for your kind cooperation