



Program

Saturday 25th of October 2025

08:50 Welcome and introduction

Carolina Ibanez, local organizing committee

Prof. Natasha Appelman-Dijkstra, clinical co-director ICFD MAS

Clinical Sessions

Chairs

Dr. Diana Ovejero, Hospital del Mar Research Institute, Barcelona, Spain

TBD

09:00 Update in the ICD FD/MAS guidelines *Prof. Natasha Appelman- Dijkstra, Leiden University Medical Center, NL*

09:20 Updates in the NIH Burosumab Study *Dr. Vivian Szymczuk, Metabolic Bone Disorders Unit, National Institutes of Health, Bethesda, MD, USA*

09:40 Combining Digital Droplet PCR and Next-Generation Sequencing for Detecting Activating GNAS Hotspot Mutations in Children with Fibrous Dysplasia/McCune-Albright Syndrome. *Prof. Wenli Lu; Shanghai Jiaotong University School of Medicine, Shanghai, China*

10:00 Future pharmacological therapies *Dr. Michael Collins, Senior Clinical Advisor, NIDCR, National Institutes of Health*

10:20 Discussions

10:50

Coffee break

11:10 Updates in the RUDY study. *Prof. Kassim Javaid, University of Oxford, Oxford, UK.*

11:30 Update on European Registries for Rare Endocrine and Bone (EuRREB) *Dr. Sophie Huisman PhD student, Leiden University Medical Center, NL*

11:50 Discussion

12:10 *Selected oral presentations*

13:15 Lunch and Posters





TRANSLATIONAL AND BASIC SCIENCE SESSION

Chairs: Prof. Mara Riminucci, Sapienza University of Rome, Rome, Italy

TBD

- 14:30** FD/MAS mouse models informing pathogenesis. *Dr. Biagio Palmisano, Sapienza University of Rome, Rome, Italy*
- 14:50** Mathematical models for predicting therapeutic response in FD lesions. *Dr. Magdalena Caballero Campos, Universidad de Córdoba, Córdoba, Spain*
- 15:10** Protein Kinase A as a Dependent Factor and Therapeutic Target in Fibrous Dysplasia. *Dr. Xhufeng Zhao; West China Hospital of Stomatology, Sichuan University, Sichuan, China*
- 15:30** Modeling Pain in FD: Advances in Mouse Studies *Prof. Anne-Marie Heegaard, University of Copenhagen, Copenhagen, Denmark*
- 15:50** Factors secreted by FD fibroblasts: new potential targets and biomarkers. *Dr. Luís Fernández de Castro, Metabolic Bone Disorders Unit, National Institutes of Health, Bethesda, MD, USA*

16:10 Discussion

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| 16:30 | Coffee break |
| 16:40 | Brainstorming sessions |
| 17:00
(till 19:00) | Patient association advocacy/patient happy hour |
| 20:30 | Community dinner |

Sunday, October 26th 2025 Community conference

08:50 Welcome

Adrienne McBride patient co-director ICFDMAS and Carolina Ibanez President Asociacion de Displasia Fibrosa

FIRST SESSION

Chair: Dr. Lucía Ugarriza, Espases, Palma de Mallorca, Spain

- 09:00** FD care in children. *Dr. Alison Boyce, Metabolic Bone Disorders Unit, NIH, Bethesda, MD, USA*
- 09:30** Endocrine care in children with FD/MAS *Dr. Irene Tarjuelo García, Hospital Universitario Sanitas La Moraleja de Madrid, Spain*
- 10:00** Endocrine care in adults with FD/MAS *Dr. Michael Collins, Senior Clinical Advisor, NIDCR, NIH*
- 10:00** Discussion

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| 11:00 | Coffee break |
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SECOND SESSION

Chair: Dr. Karen Heath, Hospital Universitario La Paz, Madrid, Spain

11:20 Pediatric Orthopedic and Trauma Management in FD/MAS (I) *Dr. Ana María Bueno Sánchez, Hospital Universitario de Getafe, Getafe, Spain*

11:35 Pediatric Orthopedic and Trauma Management in FD and (II) *Dr. Robert Stanton and Dr. Jasone Malone, Department of Orthopaedic Surgery, Nemours Children's Hospital, Orlando, FL, USA*

11:50 Orthopedic Management in Adults with FD: Trauma and intramuscular myxomas. *Dr. Lothar Seefried, University of Weizburg, Weizburg, Germany*

12:05 Maxillofacial considerations in patients with FD/MAS. *Dr. Sarina Pichardo, University Medical Centre Groningen, NL*

12:20 Ophthalmological considerations in patients with FD/MAS *Dr. Stijn Van der Meeren, Leiden University Medical Center, Leiden, NL*

12:35 Discussion

13:15 Lunch

14:30 Deep dive in sessions (round tables with doctors)

Chair: Dr. Diego Alonso, Hospital Universitario de Getafe, Getafe, Spain

15:30 Physical activity in FD *Dr. Pere Antoni Borrás Rotger, Universitat Illes Balears, Palma de Mallorca, Spain*

15:50 Imaging tests in FD/MAS: which, when and why *Dr. Manuel Parrón, Hospital Universitario La Paz, Madrid, Spain*

16:10 Special talk: Understanding FD as a doctor and a patient *Dr. José Hernández Herrero*

16:30 Discussion

16:50 Deep dive in sessions (round tables with doctors)

17:50-18:00

MEETING CLOSURE