the international consortium for FDMAS Ltd.

FD/MAS MEETING PROGRAM

FRIDAY, OCTOBER 24TH, 2025

(Subject to change)

ADF ASOCIACION DE DISPLASIA FIBROSA

ARRIVALS

Patient consultation appointments for registered attendees.
Screening of the FD/MAS Community Project video.
Photo and video warm up.

SATURDAY, OCTOBER 25TH, 2025

IC FD/MAS RESEARCH MEETING

- 8:50-9:00 Welcome & Introductions

CLINICAL SESSION (I):

Chair: TBD

- 9:00-9:20: Update in the ICD FD/MAS guidelines

Prof. Natasha Appelman- Dijkstra, Leiden University Medical Center, NL

- 9:20-9:40: Updates in the NIH Burosumab Study

Dr. Alison Boyce, Metabolic Bone Disorders Unit, National Institutes of Health, Bethesda, MD, USA

- 9:40-10:00: 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

- 10:00-10:20: Future pharmacological therapies

Dr. Michael Collins, Senior Clinical Advisor, NIDCR, National Institutes of Health

- 10:20-10:50: DISCUSSION

10:50-11:10 COFFEE BREAK

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CLINICAL SESSION (II)

- 11:10-11:30: Updates in the RUDY study

Prof. Kassim Javaid, University of Oxford, Oxford, UK.

- 11:30-11:50: Update on European Registries for Rare Endocrine and Bone (EuRREB)

Dr. Sophie Huisman, Leiden University Medical Center, NL

- 11:50-12:10: DISCUSSION

- 12:10-13:15: Selected oral communications

13:15-14:30: CONFERENCE LUNCH AND POSTER HALL

TRANSLATIONAL AND BASIC SCIENCE SESSION

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

- 14:30-14:50: FD/MAS mouse models informing pathogenesis

Dr. Biagio Palmisano, Sapienza University of Rome, Rome, Italy

- 14:50-15:10: Mathematical algorithms to predict FD lesion growth

Dra. Magdalena Caballero Campos, Universidad de Córdoba, Córdoba, Spain

- 15:10-15:30: Protein Kinase A as a Dependent Factor and Therapeutic Target in Fibrous Dysplasia

Dr. Xhuefeng Zhao; West China Hospital of Stomatology, Sichuan University, Sichuan, China

- 15:30-15:50: Modeling Pain in FD: Advances in Mouse Studies

Dr. Anne-Marie Heegaard, University of Copenhagen, Copenhagen, Denmark

- 15:50-16:10: 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

- 16:10-16:30: DISCUSSION

16:30- 16:40 COFFEE BREAK

- 16:40-18:15h: BRAINSTORMING SESSIONS (for clinical and basic scientists)

- 17:00-19h: Patient association advocacy/patient happy hour

20:30: COMMUNITY DINNER

SUNDAY, OCTOBER 26TH, 2025

COMMUNITY CONFERENCE

- 8:50-9:00 Welcome: Board president FD/MAS & IC FD/MAS

FIRST SESSION

Chair: Dr. Lucía Ugarriza, Comissió de Malalties Rares, Hospital de Son Espases, Palma de Mallorca, Spain

- 9:00-9:30: FD care in children

Dr. Vivian Szymczuk, Metabolic Bone Disorders Unit, National Institutes of Health, Bethesda, MD, USA

- 9:30-10:00: Endocrine care in children with FD/MAS

Dr. Irene Tarjuelo García, Hospital Universitario Sanitas La Moraleja de Madrid, Spain

- 10:00-10:30: Endocrine care in adults with FD/MAS

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

- 10:30-11:00: DISCUSSION

11:00-11:20 COFFEE BREAK

SECOND SESSION

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

- 11:20-11:40: Pediatric Orthopedic and Trauma Management in FD/MAS (I)

Dr. Ana María Bueno Sánchez, Hospital Universitario de Getafe, Getafe, Spain

- 11:40-12:00: Pediatric Orthopedic and Trauma Management in FD/MAS (II)

Dr. Robert Stanton and Dr. Jasone Malone, Department of Orthopaedic Surgery, Nemours Children's Hospital, Orlando, FL, USA

- 12:00-12:20: Orthopedic and Trauma Management in Adults with FD/MAS

Dr. Lothar Seefried, University of Weizburg, Weizburg, Germany

- 12:20-12:40: Ophthalmological considerations in patients with FD/MAS

Dr. Stijn Van der Meeren, Leiden University Medical Center, Leiden, NL

- 12:40-13:15: DISCUSSION

13:15-14:30: Conference lunch

- 14:30-15:30: Deep dive in sessions (round tables with doctors)

THIRD SESSION

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

- 15:30-15:50: Physical activity in FD

Dr. Pere Antoni Borrás Rotger, Universitat Illes Balears, Palma de Mallorca, Spain

- 15:50-16:10: Imaging tests in FD/MAS: which, when and why

Dr. Manuel Parrón, Hospital Universitario La Paz, Madrid, Spa

- 16:10-16:30: Special talk: Understanding FD as a doctor and a patient

Dr. José Hernández Herrero

- 16:30-16:50: DISCUSSION

- 16:50-17:50 Deep dive in sessions (round tables with doctors)

17:50h-18:00h: MEETING CLOSURE