

SECOND ANNOUNCEMENT

3rd Meeting International FD/MAS Consortium



Leiden, The Netherlands
November 15-17, 2017



The International Fibrous Dysplasia Consortium Meeting has been endorsed by the European Society of Endocrinology who has also provided financial support through an ESE Small Meeting Grant.



**European
Reference
Network**
for rare or low prevalence
complex diseases

Network
Endocrine Conditions
(Endo-ERN)

Coordinator
Leiden University Medical
Center — The Netherlands



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Bone Disorders (ERN BOND)

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Leiden, November 15-17, 2017

Wednesday 15-11-2017 Location: Lecture hall 3 LUMC	Day 1: <i>Basic aspects of Fibrous Dysplasia</i>	Speakers
12:00-12:30	Registration and Coffee	
12:30-12:40	Opening and Welcome	Dr. Neveen Hamdy, LUMC Leiden, Netherlands
12:40-13:00	Somatic mosaicism in bone tumours; GNAS mutation analysis in FD	Prof. Dr. Judith Bovee, LUMC Leiden, Netherlands
13:00-13:30	Revisiting FD through experimental models	Prof. Dr. Mara Riminucci, Sapienza University, Italy
13:30-13:50	Gain of function mutations in Gsα & endocrine disease: Studies in a mouse model of FD/MAS	Dr. Agnese Persichetti, Sapienza University, Italy
13:50-14:10	A new mouse model of FD	Mr. Luis Fernandez, NIH, Bethesda, USA
14:10- 14:30	Cytokine profiling in FD	Dr. Pablo Florenzano Valdes, NIH, Bethesda USA
14:30-14:45	Extraskeletal non-endocrine GNAS manifestations	Dr. Marlous Rotman, LUMC Leiden, the Netherlands
14:45- 15:00	Coffee Break	
15:00-15:20	Anti-NGF treatment for FD induced bone pain	Dr. Anne Marie Heegaard, Copenhagen University
15:20- 15:40	Knowledge Gaps & Future Research	Dr. Michael Collins, Dr. Neveen Hamdy
15:45- 17:00	Panel discussion	All
18:30-21:30 Restaurant "de Gaanderij"	Dutch "Stampot" Dinner and BOAT TRIP: "Leiden Canals by Night"	
Thursday 16-11-2017 Location: Poortgebouw	Day 2: <i>Clinical aspects of Fibrous Dysplasia</i>	Speakers
8:30-8:45	Registration and Coffee	
08:45- 09:15	The The PROFYDYS trial: a randomized placebo-controlled trial to test the efficacy of risedronate to treat fibrous dysplasia of bone	Prof. Roland Chapurlat, CHU Edouard-Herriot, INSERM UMR 1033, Lyon, France
09:15-09:35	Denosumab in adult FD/MAS	Dr. Natasha Appelman-Dijkstra, LUMC Leiden, NL
09:35-09:55	Bisphosphonates and Denosumab in Paediatric FD/MAS	Dr. Alison Boyce, NIH Bethesda USA
9:55- 10:15	Zoledronate in Fibrous Dysplasia: an Indian perspective	Dr. Shah Alam Khan, AIIMS Ansari Nagar, N. Delhi, India
10:15-10:30	Natural history of Bone Turnover Markers in FD	Dr. Pablo Florenzano Valdes, NIH, Bethesda USA
10:30-10:45	Gynecologic outcomes in adult women with FD/MAS	Dr. Alison Boyce, NIH Bethesda USA
10:45-11:00	Aspects of Quality of life in FD: illness perceptions & coping	Dr. Marlous Rotman, LUMC Leiden, Netherlands
11:00-11:15	Coffee Break	
11:15-11:30	NaF bone scanning: a tool for FD diagnosis and outcome prediction	Dr. Alison Boyce, NIH Bethesda USA
11:30-12:45	Panel discussion : Medical management of Fibrous Dysplasia	All
12:45-13:30	LUNCH	
13:30-14:00	Surgical Management of Polyostotic FD	Dr. Robert Stanton, Nemours Children Hosp, Orlando, FL
14:00- 14:30	Surgical Management of FD	Dr. Bas Majoor, LUMC Leiden, Netherlands
14:30-14:45	Scoliosis in FD	Tbd, NIH Bethesda USA
14:45- 15:00	Coffee Break	
15:00-15:20	Management of Craniofacial FD: an ophthalmological perspective	Dr. Stijn Genders, LUMC Leiden, Netherlands
15:20-15:40	Management of Craniofacial FD: an oro maxillary perspective	Prof. Dr. Richard van Merkesteyn, LUMC Leiden, NL
15:40- 16:40	Panel discussion: Surgical management of FD	All
16:45-18:00 Building 3, LUMC	Drinks & optional tour Leiden Anatomy Museum FREE EVENING	



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Friday 17-11-2017 Location: Poortgebouw, LUMC	Day 3: <i>Consensus Consortium Meeting</i>	Participants
08:15-09:15	Finalisation FD/MAS Care Pathway	Consortium and PAG Members
09:15-10:00	Involvement & Role of Patient Advocacy Groups within the Consortium	Consortium and PAG Members
10:00-10:15	Coffee and Start Patient Day	

Friday 17-11-2017 Location: Poortgebouw, LUMC	Day 3: <i>International Patient day</i>	Speakers
10:00-10:15	Registration and Coffee	
10:15-10:25	Opening and Welcome	Mrs. Martine Dekker-Grootveld, President Dutch Fibrous Dysplasia Patients Association
10:25 -10:40	Update: Clinical Care Pathway	Kassim Javaid, <i>NDORMS University of Oxford</i>
10:40-10:55	Update: bisphosphonates in FD	Prof. Roland Chapurlat, <i>CHU Edouard-Herriot, INSERM UMR 1033, Lyon, France</i>
10:55-11:10	Update: Denosumab in adult FD	Dr. Natasha Appelman-Dijkstra, <i>LUMC Leiden, Netherlands</i>
11:10-11:25	Update paediatric Management of FD	Dr. Allison Boyce, <i>NIH Bethesda USA</i>
11:25-11:40	Update orthopaedic Management of FD	Dr. Robert Stanton, <i>Nemours Children Hosp, Orlando, USA</i>
11:40-12:15	Update: FD Patient Advocacy Groups	Mrs. Deanne Portero, <i>Fibrous Dysplasia Foundation, USA</i>
12:15-13:15	LUNCH	
13:00-14:30	Meet the Experts Round Table Discussions Paediatric FD Cranio-Facial FD MAS Orthopaedic aspects Medical management PAGs	
14:30-15:00	<i>Wrap up Patient Day</i>	Mrs. Martine Dekker-Grootveld, President Dutch Fibrous Dysplasia Patients Association
15:00-15:15	<i>Announcement next Meeting and Closing Remarks</i>	Dr. Natasha Appelman-Dijkstra, <i>LUMC Leiden, Netherlands</i>



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