Summer Newsletter

the international consortium for FDMAS Ltd.

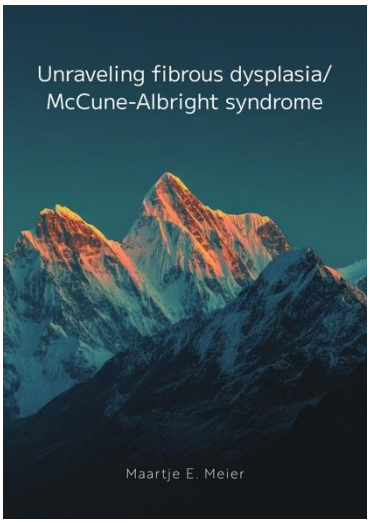
Guideline update: international FD/MAS guideline under review at JBMR

The updated international FD/MAS guideline manuscript has been submitted and is currently under review at the Journal of Bone and Mineral Research (JBMR). Thank you to all authors, Delphi participants, patient representatives and reviewers who contributed to this major consortium effort. We will share next steps as soon as peer review is complete.

New PhD thesis: Maartje E. Meier Leiden University , Leiden the Netherlands

Maartje defended her thesis at Leiden University on 21 May 2026. The thesis integrates registry-based epidemiology, clinical disease characterization, pathophysiology, biomarker studies and treatment monitoring, and translates these data into better multidisciplinary care for people living with FD/MAS.
Maartje worked in the group of consortium member prof Natasha Appelman-Dijkstra from 2019 till 2023 and is now in training to become an orthopedic surgeon.

Read the thesis



scholarlypublications.universiteitleiden.nl/handle/1887/4303723

Save the Date!

ICFDMAS Meeting 2027

24th -25th September 2027
Paris, France

More details on programme, venue and registration will follow.

Strengthen the consortium: become a member!

Membership connects patients, patient organizations, clinicians and researchers working to improve awareness, care and research for fibrous dysplasia/McCune-Albright syndrome. We welcome new individual and organizational members and encourage patient groups to share their stories for future newsletters. Membership information: www.icfdmas.com

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Publication highlights

the international consortium for FDMAS Ltd.

Recent publications in FD/MAS research

Three recent publications from consortium members highlight active progress across clinical therapeutics and preclinical disease biology: FGF23-mediated hypophosphatemia treatment, bone formation during RANKL inhibition, and comparative anti-resorptive strategies in fibrous dysplasia models.

Phase 2 burosumab trial in FD-related hypophosphatemia

de Jong O, Gun ZH, Asante-Otoo A, Elbashir II, Li X, Saboury B, Kram V, de Castro LF, MacDonald V, Boyce AM.

Bone Research. 2026 Apr 27;14(1):47.

Clinical study addressing treatment of FGF23-mediated hypophosphatemia in children and adults with fibrous dysplasia.

DOI: 10.1038/s41413-026-00523-7 | PMID: 42036408

Bone formation during RANKL inhibition in an FD mouse model

Farinacci G, Coletta I, Palmisano B, Spica E, Tavanti C, Di Cristofano S, Donsante S, et al.

Communications Biology. 2026 Apr 22. Online ahead of print.

Preclinical work exploring mechanism and pattern of bone formation during RANKL inhibition in fibrous dysplasia.

DOI: 10.1038/s42003-026-10097-z | PMID: 42020793

Anti-RANKL, zoledronate or combination therapy in FD

Palmisano B, Tavanti C, Farinacci G, Corsi A, Serafini M, Appelman-Dijkstra NM, Riminucci M.

Journal of Bone and Mineral Research. 2026 Feb 24:zjag037. Online ahead of print.

Preclinical study comparing anti-RANKL, zoledronate and combination therapy in a mouse model of fibrous dysplasia.

DOI: 10.1093/jbmr/zjag037 | PMID: 41732798

Suggestions?

Please let us now if you have a thesis. Paper or other project that you would like to see highlighted in our winter issue!

FD/MAS Research Priorities Workshop: May 2, 2026, Philadelphia. Patients, caregivers, clinicians, academic researchers, and pharmaceutical scientists were in Philadelphia to chart the future of fibrous dysplasia and McCune-Albright syndrome research. The FD/MAS Research Priorities Workshop, organized by the FD/MAS Alliance and chaired Dr. Michael Collins, brought together a diverse and deeply invested community with a shared mission: to identify what matters most to the people living with FD/MAS and to align the scientific community around those priorities.

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Patient association spotlight series

the international consortium for FDMAS Ltd.

From now on, each newsletter will introduce one of the patient associations within our global FD/MAS community. We start with the GULI (FD/MAS) Care Center, a patient-led nonprofit organization connecting families, clinicians and researchers across China.

Patient Association Spotlight: GULI (FD/MAS) Care Center, China

Established in December 2021 through a joint initiative of the Chinese FD/MAS patient community and the Cord Rare Disease Center, GULI provides patient support, reliable medical information, community networking and access pathways to specialist care. Its vision is simple and powerful: to inspire hope for all individuals living with FD/MAS.

蔻德罕见病中心
Chinese Organization for Rare Disorders

骨力(FD/MAS)关爱中心

>1,200 members as of June 2026
>2,826 WeChat followers
62 clinical Centers ivolved

Education and reliable information

- China's first FD/MAS clinical checklist and educational animation
- WeChat articles, visual materials and research updates for families and clinicians
- Resources aimed at improving understanding and reducing misdiagnosis

Improving access to care

- China's first multidisciplinary MAS treatment center was established in January 2024
- Fast-track inpatient and outpatient access pathways with leading hospitals
- A dedicated MAS specialty clinic is already in operation

Community support and exchange

- Online doctor–patient sessions and patient-sharing meetings
- In-person patient events across Shanghai, Hangzhou, Tianjin, Suzhou and Chengdu
- The Young Doctors Forum links families, early-career physicians and senior experts

Research translation and collaboration

- Official patient community hub of China's first FD/MAS clinical network
- Patient–physician engagement and data-driven research initiatives
- A clear focus on accelerating research translation to improve care and quality of life