



FOR IMMEDIATE RELEASE

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Global collaboration launches the International Consortium for Fibrous Dysplasia and McCune-Albright Syndrome

[FD/MAS Alliance](#), [Patiëntenvereniging Fibreuze Dysplasie](#), [ASOCIACIÓN DE DISPLASIA FIBROSA – ADF](#), [Fibrous Dysplasia Support Society UK](#), and [European Association for McCune-Albright Syndrome](#) are announcing the launch of the International Consortium for Fibrous Dysplasia and McCune-Albright syndrome Ltd. (ICFDMAS).

Fibrous dysplasia and McCune-Albright syndrome (FD|MAS) is a rare disease that can cause a wide range of issues. It is genetic, but it is not inherited from family and cannot be passed down. It can be traced to a single random mutation that occurs in the womb as a fetus develops. Symptoms range from mild to severe, and people living with FD|MAS can live full and prosperous lives. There is no cure, however, and there are no treatments to stop or slow a major symptom of the disease, the growth of malformed bones. These malformed bones cause chronic pain, weak bones that are easy to fracture, and differently-shaped bodies. Patients turn to a range of stopgap treatments, like multiple surgeries, hormonal therapeutics, and medical device implants to try and manage their disease.

The mission of the International Consortium for FD/MAS is to improve the care and find solutions for the unmet needs of patients and their carers through the promotion of multi-stakeholder, collaborative, and patient-centric clinical, translational, and basic research. The International Consortium for FD/MAS will encourage the testing and development of potential cures and treatments. Also it will promote the development of evidence-based standards of care. The consortium aims to improve access to information worldwide through dissemination and education initiatives. Finally the consortium will support the development of cooperative scientific studies and initiatives with promise to serve the global FD/MAS patient community.

Already, the ICFDMAS has published “[Best practice management guidelines for fibrous dysplasia/McCune-Albright syndrome](#)” in Orphanet Journal of Rare Diseases and led to 5 collaborative research publications. In addition to a host of international patient advocacy organizations involved, researchers from the National Institutes of Health, Leiden University in the Netherlands, University Claude Bernard-Lyon in France, Sapienze University of Rome in Italy and University of Oxford, England are also involved.

In honor of FD/MAS Global Awareness Week (20-27th February) the ICFDMAS has launched a website complete with resources and information for patients, caregivers, and clinicians. For more information about the ICFDMAS or to join please visit www.icfdmas.com or contact us at info@icfdmas.com

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About FD/MAS Alliance The Fibrous Dysplasia Foundation (FDF) dba FD/MAS Alliance is a community-led 501(c)3 nonprofit that fights back against fibrous dysplasia and McCune-Albright syndrome (FD/MAS) based in the United States serves people affected by FD/MAS through programs of research, education, and advocacy.

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Over Patiëntenvereniging Fibreuze Dysplasie Een 100% vrijwilligersorganisatie voor en door patiënten. Wij staan voor belangenbehartiging, informatievoorziening en lotgenotencontact voor patiënten met Fibreuze Dysplasie en McCune Albright Syndroom, en hun naasten. Dit uit zich in:

Het vergroten van de kennis bij patiënt en zorgverlener, het bevorderen van een snelle en juiste diagnose van de ziekte, het bevorderen van onderzoek naar Fibreuze Dysplasie en McCune-Albright Syndroom en het onder de aandacht brengen van deze zeldzame ziekte in het algemeen.

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Sobre la Asociación de Displasia Fibrosa (ADF). La ADF es una entidad sin ánimo de lucro que congrega a afectados, familiares y personas sensibilizadas con la Displasia Fibrosa y Síndrome de McCune-Albright. Nuestra misión es promover actuaciones para mejorar la vida de los pacientes y sus cuidadores. Fomentamos la figura del "Paciente Experto" cuyo objetivo es el conocimiento de su propia enfermedad. Promovemos actividades para la divulgación de información válida y rigurosa sobre la DFMAS. Trabajamos en la creación de una red de expertos profesionales en DFMAS. Lanzamos campañas para dar visibilidad a la enfermedad y concienciar a la sociedad sobre la enfermedad. Impulsamos la investigación científica. Establecemos vínculos de coordinación con otras entidades tanto nacionales como internacionales que permitan la actuación conjunta para la mejora de la calidad de vida de los pacientes con DFMAS.

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About Fibrous Dysplasia Support Society UK (FDSSUK) The Fibrous Dysplasia Support Society (FDSS) exists to provide information and support by sharing our knowledge and experience of the condition with those who would like to know more. To encourage, promote and assist a better understanding of Fibrous Dysplasia (including its associated conditions) and its possible treatments among patients and their carers. To promote increased awareness of the condition amongst medical professionals. To actively encourage people with the condition to meet others affected and to share their experiences. FDSSUK have a medical advisory board that provides advice for individuals with FD/MAS.

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European Association for McCune- Albright Syndrome (EAMAS) European Association for Mc Cune-Albright Syndrome - Fibrous Dysplasia (EAMAS). L'Associazione, senza scopo di lucro, è impegnata nel divulgare ed organizzare le informazioni in merito alla condizione clinica in modo che possano essere utili alla comunità scientifica, per l'assistenza dei pazienti e dei loro familiari. L'Associazione promuove la ricerca scientifica e fornisce supporto ed assistenza ai pazienti ed alle loro famiglie.