

Charter of the International Consortium for Fibrous Dysplasia and McCune Albright Syndrome (ICFDMAS)

Document History

Charter document first drafted over the course of 2018 and early 2019 by a Terms of Reference Writing Group comprised of fibrous dysplasia/McCune-Albright syndrome (FD/MAS) patient advocates and researchers. Charter reviewed by the International Consortium for Fibrous Dysplasia and McCune Albright Syndrome (ICFDMAS) stakeholders several times and discussed during the ICFDMAS Florence meeting in May 2019. Revised version sent to core writing group in August and discussed during tel con in September 2019. Revised charter sent to core group and discussed during ICFDMAS consortium meeting at ASBMR Orlando 2019. Charter revised to incorporate descriptions on membership and minor other changes, *reviewed and request to approve by writing committee in May 2022. Reviewed again in January 2025 by the ICFDMAS board of directors*

Background

The mission of the International Consortium for Fibrous Dysplasia and McCune Albright Syndrome (ICFDMAS) is to improve the care and find solutions for the unmet needs of patients with fibrous dysplasia/McCune-Albright syndrome (FD/MAS) and their carers through the promotion of multi-stakeholder, collaborative, and patient-centric clinical, translational, and basic research.

The International Consortium for Fibrous Dysplasia and McCune Albright Syndrome (ICFDMAS) will pursue the testing and development of potential cures, treatments and devices, develop and maintain evidence-based standards of care, improve access to high-quality care worldwide through dissemination and education initiatives, and generally support cooperative scientific studies and initiatives with promise to serve the global FD/MAS patient community.

The idea of ICFDMAS emerged at a multidisciplinary workshop attended by FD/MAS patients and clinical researchers in Oxford, England 2015. Following two days of collaborative workshops, a consensus was reached to create an international, multi-stakeholder partnership to advance research and clinical care in FD/MAS. The publication announcing this outcome extended an invitation for others to join this partnership to support improving outcomes for patients with FD/MAS.¹

¹ Improving patient outcomes in fibrous dysplasia/McCune-Albright syndrome: an international multidisciplinary workshop to inform an international partnership, <https://www.ncbi.nlm.nih.gov/pubmed/28243882>

The partnership formally reconvened again in 2016 at the 2nd International FD/MAS Initiative Meeting in Lyon, France. At this meeting, clinician and patient representatives exchanged information on their respective projects and priorities, and continued to advance the group's first shared project, the development of an international clinical care pathway. ²

The partnership formally reconvened again in 2017, at the 3rd Meeting of the International Consortium for Fibrous Dysplasia and McCune Albright Syndrome (ICFDMAS) in Leiden, the Netherlands. ³ The program included two days of presentations of basic and clinical research on FD/MAS, working time to finalize the international clinical pathway and companion checklist for patients, and a day of patient community education and engagement for the Dutch patient community. At this conference, there was a direct discussion between the partners of the requisite roles and relationships of different stakeholders in order to make ICFDMAS optimally successful for all parties.

In a follow-up teleconference in 2018, a consensus emerged that it was the appropriate time to clarify and formalize the collaborative structure of ICFDMAS. Deanna Portero (Fibrous Dysplasia Foundation) and Kassim Javaid (University of Oxford) volunteered to develop a drafting process for ICFDMAS's Terms of Reference. Dr. Natasha Appelman-Dijkstra (Leiden University Medical Center), Michael Cantwell (Fibrous Dysplasia Support Society UK), Dr. Michael Collins (National Institutes of Health), Valter Dal Pos (Associazione Europea amici della Sindrome di McCune-Albright) and Martine Dekker (Patiëntenvereniging Fibreuze Dysplasie) volunteered to serve in the drafting process. The governance structure of ICFDMAS was modeled after examples of successful networks around the world that have fostered successful international collaborations, and continue this facilitation role for their community. In 2019 the charter was discussed during several telcons and on the Florence 2019 Meeting. There it was decided that the format was reaching final stage and the charter should be finalized, considering the pre-work of the FDF this shall be prepared by FDF in collaboration with Michael Cantwell (FD Support Society UK). As Deanna Portero has stepped down as director of FDF, Dr Natasha Appelman-Dijkstra took over the writing process.

The founding members of the International Consortium for Fibrous Dysplasia and McCune Albright Syndrome (ICFDMAS) selected the Executive Committee. Members of the Executive Committee were elected, and assigned staggered terms of 3 years, 4 years, and 5 years, assigned randomly.

² Patient Organizations & Doctors Gather to Guide Progress for Better Treatment on a Global Scale, <https://www.fibrousdysplasia.org/fd-initiative-lyon/>

³ 3rd International FD/MAS Meeting in the Netherlands, <https://www.fibrousdysplasia.org/2017-leiden-fdmas-meeting/>; Programme, <https://endo-ern.eu/wp-content/uploads/2017/10/Second-announcement-FD-meeting-Leiden-29-09-2017.pdf>

Founding members (individuals and organizations* in 2018):

Michael Collins, MD	Roland Chapurlat, MD
Natasha Appelman-Dijkstra, MD, PhD	Alison Boyce, MD
Martine Dekker	Michael Cantwell
Patiëntenvereniging Fibreuze Dysplasie*	FDSSUK*
Fibrous Dysplasia Foundation (DBA FD/MAS Alliance)*	Valter Dal Pos
Kassim Javaid, MBBS, BMedSci, MRCP, PhD	EAMAS*
Mara Riminucci, MD, PhD	Asociación de Displasia Fibrosa*
	Anne-Marie Heegaard MD, PhD

Executive committee 2022:

Chair or co-chairs: Dr. Natasha Appelman-Dijkstra and Adrienne McBride

Secretary (deputy chair): Tovah Burstein (acting as)

Communications: Martine Dekker (acting as)

Member: Dr. Michael Collins

1 Article I – Organization and Affiliation

- 1.1 This organization is known as the International Consortium for Fibrous Dysplasia and McCune Albright Syndrome (ICFDMAS). It is a consortium with the mission to improve the care and find solutions for the unmet needs of patients with fibrous dysplasia/McCune-Albright syndrome (FD/MAS) and their carers through the promotion of multi-stakeholder, collaborative, and patient-centric clinical, translational, and basic research. The International Consortium for Fibrous Dysplasia and McCune Albright Syndrome (ICFDMAS) will encourage the development of potential cures, treatments, and devices, develop and maintain evidence-based standards of care, improve access to high-quality care worldwide through dissemination and education initiatives, and generally support cooperative scientific studies and initiatives with the promise to serve the global FD/MAS patient community.
- 1.2 ICFDMAS is organized as an LTD of interested parties who work together to support projects to advance research and care for FD/MAS patients worldwide. The views of ICFDMAS do not necessarily represent the views of the institutions and organizations with which members are affiliated.

2 Article II – Membership

- 2.1 A Member of ICFDMAS agrees to sign a membership form and agrees to work with ICFDMAS within the framework of this charter to further advance the aims and objectives of ICFDMAS.
- 2.2 The new membership will then be voted on by the Executive Committee.

- 2.3 To apply for membership a completed membership form (to be added as Appendix 1) should be signed and submitted to the Secretary of ICFDMAS. The authority to approve membership forms will reside with the Executive Committee unless duly delegated to a body designated by the Executive Committee.
- 2.4 On becoming a member, members will receive a notification and will be listed as a member on the ICFDMAS website (name and location), unless requested otherwise. Organizational members may be required to provide their logo for the ICFDMAS website.
- 2.5 Members who wish to terminate their membership should contact the Secretary. Membership will cease after 30 days from receiving the termination request and the members' information will be removed from the website within this period.
- 2.6 Members will have open access to reports, newsletters, work plans, and updates on activities.
- 2.7 Members must not, whether knowingly or negligently, act in a way that could bring ICFDMAS into disrepute or lead to a possible loss of public confidence.
- 2.8 If a member consistently fails to participate in consortium activities (minimum activity level 1 meeting every 2 till 3 years, this can be online or in person), is found to have brought the Consortium into disrepute, or could possibly bring the Consortium into disrepute, then the member will be contacted by the Chair of the Executive Committee in writing to request an explanation of the reasons for their actions and how this can be resolved. The member will be given a period of 30 days to resolve the issue(s) or explain why they feel they have not contravened the obligations in article 2.6. If the member does not comply then they will be asked to remove the ICFDMAS logo and any other association from any publishable materials, i.e., websites, newsletters, etc, and their membership will be terminated forthwith following a two-thirds vote of the Executive Committee members who have convened with a standard quorum.
- 2.9 Members will not claim to be a member of the Consortium without first having signed the membership form referred to in article 2.2, and receiving written confirmation of application approval from ICFDMAS leadership.
- 2.10 Members must comply with all relevant known national and international data protection, privacy, and ethical laws and guidelines.
- 2.11 Members can only use the Consortium name after permission of the Executive committee. Corporate members will be presented on the consortium's website.

3 Article III – Membership Meetings

- 3.1 Membership meeting: The authority to set the date and place of in-person membership meetings will lie with the Executive Committee. This will be announced at least three months in advance.
- 3.2 Any voting matters for general membership must have virtual participation options.
- 3.3 Special meetings: Special meetings (either in person or virtual) may be called by the Executive Committee.
- 3.4 Notice: Notice of meeting agendas and supporting documents for each meeting will be given to each member, by (electronic) mail, not less than fourteen (14) days before the meeting.

4 Article IV – Executive Committee 4.1

- 4.1 The Executive Committee is responsible for providing overall policy and strategic direction to the ICFDMAS, oversees activities and progress, and delegates responsibility for day-to-day operations to

any committees that the Executive Committee commissions.

The Executive Committee will have an odd number of seats with at least 3 members. The Executive Committee receives no compensation.

Members of the Executive Committee are elected as private individuals and not representatives of their home institution or organization. Corporate members are not eligible to serve on the Executive Committee.

- 4.2 Only individual members can be elected to the Executive Committee. There will be two seats reserved for each of the following constituencies: scientists with an interest in FD/MAS (e.g. PhDs), clinical researchers (e.g. MDs), and patient advocates (personal tie to FD/MAS, or representative from a patient organization). One of those reserved seats can go unclaimed, but at least one representative from each of those categories is required.
- 4.3 One of the seats reserved for patient advocates will be reserved for an individual member who leads a national or multi-national patient organization and be filled via rotation. The initial order of the rotation will be established randomly. The maintenance of the list of eligible individual members to serve in this seat as patient organizations join and leave the consortium, and all other rules pertaining to this rotation system, will be the prerogative of the Secretary. The remaining seats of the Executive Committee, including the additional reserved seat for a patient advocate, will be established via general election by the general membership.
- 4.4 The Executive Committee will meet at least annually, either in person or virtually, at an agreed-upon time and place. One of these meetings will be designated as the annual Executive Meeting. The annual Executive Committee meeting requires that membership is informed of the meeting at least 6 weeks in advance.
- 4.5 Ratification of the election of new Executive Committee members or re-election of current Executive Committee members to an additional term after the requisite 30-month waiting period will occur as the final item of business at the annual Executive Committee meeting. Executive Committee members will be elected by a vote of the current ICFDMAS members. Nominations may be made by any member of ICFDMAS, including self-nomination, and should be sent to the Secretary no later than 4 weeks before the annual meeting of the Executive Committee. Each candidate must declare and be approved by Exec Committee what their representative affiliation is in advance of the ballot (i.e. basic researcher, clinical researcher or patient advocate). All members will confidentially vote to identify their preferred candidates, casting as many votes as there are vacancies on the Executive Committee, and each candidate's vote total will be tabulated. First, reserved seats will be filled with the eligible candidates with the largest number of votes within that representation category. Any remaining open seats on the Executive Committee will go to the candidate(s) with the largest number of votes, irrespective of constituency. Ties will be broken in a random manner determined by the reigning Executive Committee.
- 4.6 All Executive Committee members will serve 5-year terms but are eligible for re-election after the 30-month waiting period.
- 4.7 For any Executive Committee meeting, a quorum must be attended by at least two-thirds of the Executive Committee members before business can be transacted or motions made or passed. Two-thirds shall be the default quorum for all Executive Committee business unless otherwise specified elsewhere in this charter. Unless specified elsewhere in this charter, the decision-making threshold for matters discussed in a duly convened Executive Committee meeting shall be a simple majority.

- 4.8 For any Executive Committee meeting, an Executive Committee meeting requires that each Executive Committee member have written notice of the agenda at least two weeks in advance, and all meeting materials at least 3 days in advance.
- 4.9 There will be two officers of the Executive Committee consisting of a Chair and a Secretary. Their duties are as follows:
- The Chair will convene regularly scheduled Executive Committee meetings, will have primary responsibility for the development of Executive Committee agendas, and will preside or arrange for a member of the Executive Committee to preside at each meeting as Deputy Chair.
 - The Secretary will provide all supporting documentation and information to the Executive Committee at their regular meetings, keeping records of Executive Committee actions, including overseeing the taking of minutes at all Executive Committee meetings, sending out meeting announcements, distributing copies of minutes and the agenda to the Executive Committee and members, coordinating nomination and voting procedures, and assuring that records are maintained. The Secretary will provide administrative support, communications support (web site, newsletter), support of fiscal procedures, and development of reports to ICFDMAS members and the general public. The Executive Committee must approve external reports.
 - Following the annual meeting of the Executive Committee and the ratification of any new Executive Committee members, there will be an annual election of officers by the Executive Committee within 4 weeks. Any member of the Executive Committee is eligible to run for the Chair or Secretary.
 - Executive Committee elections will be held by confidential ballot, coordinated by the current Secretary if he or she is not seeking reelection, or by an Executive Committee member appointed by the Secretary who is not running for Chair or Secretary, or a general member appointed by the Secretary if all Executive Committee members run for officer positions. Elections may be virtual and will take effect immediately upon the ratification by the coordinating party.
 - In the case of the resignation of the Chair or Secretary, or removal from the post by a majority vote of the Executive Committee, the remaining officer will appoint an interim officer until an election can be held, within 4 weeks.
- 4.10 When an unplanned vacancy on the Executive Committee exists, nominations for new members may be received from present ICFDMAS members by the Secretary four weeks in advance of an Executive Committee meeting. These nominations will be sent out to the members to be voted upon and the results announced at the end of the next Executive Committee meeting. These vacancies will be filled only to the end of the original particular Executive Committee member's term. Separate ballots may be held to fulfill stakeholder requirements, as required. Virtual participation options must be provided.
- 4.11 Resignation from the Executive Committee must be in writing and received by the Secretary. An Executive Committee member will be removed from the Executive Committee if s/he has excess absences from regular Executive Committee meetings following a three-quarter vote of the remaining Executive Committee members following an appeal. An Executive Committee member may be removed for other reasons by a three-fourths vote of the remaining Executive Committee members following an appeal. All appeals must be submitted to the Chair of the Executive Committee on request.

5 Article V – Subcommittees and Advisory Boards

- 5.1 The Executive Committee may create subcommittees, task forces, and advisory boards as needed, such as fundraising, membership, conference, project-based, etc.
- 5.2 The Executive Committee Chair appoints all subcommittee and advisory board chairs upon agreement by the Executive Committee. All subcommittees and advisory boards will report to the Executive Committee.
- 5.3 Subcommittees and advisory boards will be required to report and provide recommendations to the Executive Committee based on the remit of the advisory board as defined by the Executive Committee.
- 5.4 Subcommittees and advisory may be created or disbanded by the Executive Committee by a simple majority vote in any validly convened meeting.

6 Article VI – Date of Activation of Bylaws and Interim Officers

- 6.1 When approved by at least two-thirds of the votes cast by the Executive Committee, these bylaws will become active and adopted at the time of the business meeting.

7 Article VII – Amendment of Charter Statement

- 7.1 With the exception of bylaws pertaining to Executive Committee election, these bylaws may be amended when necessary by a two-thirds majority of the Executive Committee. A quorum of at least three-fourths is required. Proposed amendments must be submitted to the Secretary to be sent out with regular Executive Committee announcements.
- 7.2 Bylaws pertaining to the election of the Executive Committee may be amended when necessary by a simple majority of the membership of ICFDMAS. A quorum of at least two-thirds is required. Proposed amendments must be submitted to the Secretary to be sent out with regular Executive Committee announcements.

8 Article VIII – Dissolution of the International Consortium for Fibrous Dysplasia and McCune Albright Syndrome (ICFDMAS)

- 8.1 The dissolution of ICFDMAS will be decided by an affirmative vote by a written ballot of three-fourths of the votes of the members of ICFDMAS. A quorum of at least two-thirds is required. Proposed dissolution must be submitted to the Secretary to be sent out with regular Executive Committee announcements.
- 8.2 If ICFDMAS is wound up, all of the organization's assets which would otherwise be available to its members generally shall be transferred on its winding up either to one or more bodies with objects similar to that of ICFDMAS or to another body the objects of which are the promotion of charity and anything incidental or conducive thereto (whether or not the body is a member of the Consortium). Such bodies will be selected by the Executive Committee.

These Bylaws have been approved following a meeting and voted on by the Founding Members of the International Consortium for Fibrous Dysplasia and McCune Albright Syndrome (ICFDMAS) on July 14th 2022. The revised Bylaws have been circulated to the members and will be discussed during the 2025 Madrid meeting.

APPENDIX 1: Membership Form

APPLICATION MEMBERSHIP INTERNATIONAL CONSORTIUM FD/MAS

WWW.ICFDMAS.COM

PERSONAL INFORMATION	
Full name:	
Email address:	
Organization:	
Reason for applying:	
Memberships of professional societies:	
Primary field of interest:	
I am a:	<ul style="list-style-type: none">• Clinician• Clinician - scientist• Basic researcher• Patient organization representative*• PhD student

DECLARATION AND SIGNATURE
<p>I, _____, hereby declare that the above information provided is true and complete to the best of my knowledge. I agree to abide by the consortium's Terms of Reference. I understand that any false information may result in the denial of membership or termination if already accepted.</p> <p>If membership is granted I approve that my name will be listed as a consortium member on the ICFDMAS website.</p>
Signature:
Date:

Please send this application with a C.V. to info@icfdmas.com

* For patient organization representatives there is no need for a CV.

Please provide relevant links to your website and/or social media platform.