

PLEASE READ THE FOLLOWING INFORMATION CAREFULLY. IN UTILIZING THIS SERVICE, YOU REPRESENT THAT YOU ARE AT LEAST EIGHTEEN (18) YEARS OF AGE, AND YOU ACKNOWLEDGE THAT YOU UNDERSTAND AND ACCEPT THE FOLLOWING TERMS AND CONDITIONS. IN COMPLIANCE WITH THE CHILDREN'S ONLINE PRIVACY PROTECTION ACT, YOU MUST BE EIGHTEEN (18) YEARS OF AGE OR OLDER TO SUBMIT PERSONAL MEDICAL DATA AND INFORMATION. IF YOU DO NOT ACCEPT THESE TERMS AND CONDITIONS, YOU MAY NOT ACCESS THIS SITE OR UTILIZE ANY OF THE SERVICES PROVIDED ON OR THROUGH THIS SITE.

[embedded ["How to Join" screenshare video](#)]

The FIBROUS DYSPLASIA/MCCUNE-ALBRIGHT SYNDROME Patient Registry ("FD/MAS Registry") is a project of the FIBROUS DYSPLASIA FOUNDATION to collect patient information and medical information concerning FIBROUS DYSPLASIA/MCCUNE-ALBRIGHT SYNDROME (FD/MAS) in order to accelerate research and find better treatments and ultimately a cure for these conditions.

#### 1. General; Purpose and Acceptance of Terms and Conditions

a. General. Use of the FD/MAS Registry website (the "Website") and the services associated with the FD/MAS Registry website (the "Services") is governed by the following terms and conditions herein (the "Terms and Conditions") and an informed consent document (the "Informed Consent"), both of which you must read before joining the FD/MAS Patient Registry. All pages within the Website are owned and operated by the FIBROUS DYSPLASIA FOUNDATION (The FIBROUS DYSPLASIA FOUNDATION together with its members, directors, and affiliated entities are referred to collectively herein as "FDF") or with the permission and cooperation of approved and trusted third-party partners.

b. Purpose. The purpose of the Website is to allow individuals, families, and medical and research providers to enter certain information to the FD/MAS Registry. The voluntary information provided by the registrant, during registration, is maintained in a secured database and identifiable data will not be shared outside the FDF without the registrant's express consent. However, the FDF may allow researchers and other approved third parties to search and access de-identified information.

c. Acceptance of Terms and Conditions. By using the Website, you represent that you accept and agree that you have read the Terms and Conditions and the Informed Consent documents, understand them, and that you agree to and have the legal capacity to be bound by them. These Terms and Conditions constitute a legal agreement between you and the FDF. The FDF reserves the right to modify these Terms and Conditions at any time in its sole discretion, and without prior notice, by posting amended terms on this Website. We encourage you to review the Terms and Conditions periodically for any

updates or changes. If you do not agree to be bound by the Terms and Conditions, you may not use the Website.

## 2. Ownership

All FD/MAS Registry-generated content available at the Website, including without limitation, any information, software, photographs, images, video, audio, graphics, or text on the Website ("Content"), and all patent, copyright, trademark, trade dress, domain name, trade secret, and other proprietary rights therein are the sole property of the FDF or used by the FDF with the permission of the owner of such content. You agree to abide by all intellectual property and copyright laws protecting those property rights and any additional restrictions set forth on the Website in relation to the content, source code, and other elements of the Website.

## 3. Use of the Website

a. Legal Capacity. You may use the Website to register to be included in the FD/MAS Registry, if you are at least eighteen (18) years old or older or possess legal parental or guardian consent; that you are fully able and competent to enter into the terms and conditions set forth in these Terms and Conditions and are otherwise capable of forming legally binding agreements under applicable law; and that you agree to be bound by these Terms and Conditions. If you are not competent to form legally binding agreements, do not use this Website.

b. True, accurate and complete information. If you register to use the Website, you agree to provide true, accurate, and complete registration information.

c. Lawful Use. You agree to use the Website for lawful purposes only. You shall comply with all federal, state, and local laws applicable to the use of this Website and shall not use the Website to engage in any prohibited conduct. Prohibited conduct, broadly stated, is any conduct (i) that is unlawful, infringing, tortious, fraudulent, abusive, harassing, or otherwise harmful to the FD/MAS Registry, the FDF, or any other party or property; (ii) that violates another party's intellectual property, privacy, or other rights; or (iii) that otherwise interferes with the operation, use or enjoyment of any service, system, or other property. Without limiting the generality of the foregoing, any information provided by you in connection with use of the Website: (1) shall not be false, fraudulent, inaccurate, or misleading; (2) shall not be obscene or indecent; (3) shall not contain any viruses, Trojan horses, worms, time bombs, spiders, or other computer programming routines that are intended to damage, detrimentally interfere with, surreptitiously intercept or expropriate any system, data, or personal information; (4) shall not infringe on any of the FDF's or other third party's copyright, patent, trademark, trade secret, or other proprietary rights or rights of publicity or privacy; (5) shall not be defamatory, libelous, unlawfully threatening or harassing; and (6) shall not create liability for the FDF or cause us to lose the services of our Internet service providers or other suppliers. You may not take any action that imposes an

unreasonable burden upon the infrastructure used to support the Website, including but not limited to unsolicited e-mail, also called spam.

d. Website for Allowable Activities (defined herein) only. The Website is for the use of registered users only. Specifically, individuals, families, providers, and approved data curators can use the Website to register and update a participant record (the "Allowable Activities"). The Website cannot be used in connection with any other endeavor outside of the Allowable Activities, including, but not limited to blogging. Specifically, users shall not disclose, post, publish, display, or transmit any of the Website content, without the written consent of the FDF. Users also shall, at all times, maintain all de-identified information received from the Website in the strictest of confidence.

e. No Unauthorized Use. You may not attempt to gain unauthorized access to this Website or any services, other accounts, computer systems, or networks connected to any server or to any of the Services, through hacking, password mining, or any other means.

#### 4. User Conduct and Responsibility

a. Security. You are solely responsible for the security of your password and your account, and are fully responsible for all activities that occur under your password or account with or without your knowledge. You may not knowingly provide your login and password information to another person. You agree to immediately change your password, and notify the FD/MAS Registry Coordinator via email at [registry@fibrousdysplasia.org](mailto:registry@fibrousdysplasia.org) of potential unauthorized use of your password or account or any other breach of security. The FDF will not be liable for any loss or damage arising from your failure to comply. Certain portions of the Website and information contained on the Website may be accessible only to authorized registered users or to affiliates, service providers, or other business partners of the FDF, or may otherwise be password restricted. You agree not to (i) gain or attempt to gain unauthorized access to such portions of the Website or to information contained in such sections of the Website; (ii) obtain or attempt to obtain confidential, proprietary, and/or personal information stored on the Website; (iii) distribute passwords to unregistered or unauthorized users; or (iv) make any unauthorized use of the Website or information accessible on the Website. The FDF reserves the right to deny or revoke access to the Services, in whole or in part, if the FDF reasonably believes that you are in breach of these Terms and Conditions, or are otherwise using or accessing the Services in any manner inconsistent with the Terms and Conditions.

b. User Submitted Content. You acknowledge and agree that, upon creation of a profile on the Website and registration or registration as a provider, your submitted content (each submission individually, and all submissions, collectively, referred to herein as the "User Submission") may be available for viewing by other registered users or to affiliates, service providers, or other business partners of the FDF and the FD/MAS Registry for research, statistical, study, and evaluation purposes, with the exception of a set of identifying submissions like name, phone number, email address and street address. Notwithstanding

the foregoing, however, the FD/MAS Registry makes no representation or guaranty that your profile or provider information will be reviewed.

The FD/MAS Registry is not in any way associated with or responsible for content posted on or transmitted to the Website by users, including, but not limited to, User Submissions. The FDF has the right, but not the obligation, to monitor and verify content posted on or transmitted to the Website for any reason, and reserves the right to remove anything that is, in its sole discretion, unacceptable, inappropriate, or not in compliance with these Terms and Conditions; to disclose data to law enforcement agencies or authorities who may investigate reports of misuse or abuse of this Website; and to terminate any User's access to the Website at any time, without prior notice.

Each respondent acknowledges and agrees that the FD/MAS Registry is not required to edit or review any information or content posted, submitted, or otherwise transmitted by users. However, the FDF reserves the right, in its sole discretion, to verify and correct any errors, inaccuracies, or omissions in any portion of the Website or content posted thereon or submitted or otherwise transmitted thereto, and all such content may be subject to FDF approval. The FDF reserves the right, at any time, for any reason, to reject, suspend, cancel, or remove content, and neither the FDF, nor its employees, consultants nor other agents will have any liability for taking such actions.

You are responsible for any content you post, publish, display, or otherwise transmit to the Website. You agree not to transmit or otherwise make available on the Website any personal information of any individual or any material protected by copyright, trademark, publicity, privacy, or other proprietary right without the express permission of such individual or the owner of such rights, respectively. The burden of determining that transmission of the information is permissible, or that the material is not protected by such rights, is on you, the user. You shall be liable for and shall indemnify and hold the FDF harmless for any damages resulting from any infringement of copyrights, trademarks, proprietary rights, violation of privacy or publicity rights, or any other harm resulting from your submissions to, or transmission of information from, the Website.

By submitting material to any area of the Website, you expressly grant to the FDF the royalty-free, perpetual, irrevocable, non-exclusive right and license to use, reproduce, modify, adapt, publish, translate, and distribute such material (in whole or in part) worldwide, in accordance with the Term and Conditions and Informed Consent documents.

You further understand and acknowledge that you may be exposed to information that is inaccurate or otherwise objectionable, and you agree to waive and hereby do waive, any legal or equitable rights or remedies you have or may have against the FDF with respect thereto, and agree to indemnify and hold the FDF and its partners harmless to the fullest extent allowed by law regarding all matters related to your use of the Website, whether as a registered provider in submitting User Submissions and/or

creating a profile, or as a representative of an institution using the Website for informational and educational purposes. Users may report abuses of the Website to the FD/MAS Registry Coordinator with sufficient detail identifying the abusive conduct or content, so that the FDF may determine, in its sole discretion, whether to take action with respect to such alleged abuse.

You are solely responsible for and will exercise caution, discretion, common sense and judgment in using and accessing the Website and all content contained therein. You are solely responsible for any equipment necessary to access and use the Website.

c. Cooperation. You agree to cooperate fully with the FDF to investigate any suspected or actual activity that is in breach of these Terms and Conditions.

d. Research Studies, Clinical Trials, and Other Developments. It is the responsibility of all users to stay informed regarding clinical trials, research, and other developments of interest. Although the FD/MAS Registry will attempt to distribute relevant information regarding research studies and clinical trials to users based on the information provided in the user's profile, the FDF assumes no responsibility for informing users regarding all such studies and trials, and makes no guaranty as to the completeness or accuracy of such information. The FDF also assumes no responsibility for connecting any user with the provider of a research study or clinical trial, but will make every effort to inform users of upcoming research studies or clinical trials. Furthermore, the FDF assumes no responsibility for ensuring the qualification of a user or participation of any user in any such study or trial. It is the responsibility of each user to contact the relevant investigators and pursue participation in a study or trial.

The value and relevance of the information provided by the FD/MAS Registry is directly linked to the information provided by users in their respective profiles and registration. It is your responsibility to provide complete and accurate information, and to update your profile information as appropriate, so that you can receive relevant and current information.

e. Risk of Using the Website, Email, Hard Copies, and the Internet. You assume total responsibility and risk for your use of the Website, email, sending information via hard copies, and the Internet. You acknowledge and agree that any uploads or transmission you make to, from, or through these means may be intercepted and used by an unauthorized third party and that all of the risk associated with these activities is solely yours.

f. Links to Other Websites. The Website may contain links to other Websites that are not under the control of the FD/MAS Registry. The FD/MAS Registry is not responsible for the contents of any linked website or any link contained in a linked Website, or any changes or updates to such websites. The inclusion of any link does not imply endorsement by the FD/MAS Registry. It is up to you to take

precautions to ensure that whatever you select for your use is free of viruses, worms, Trojan horses, and other items of a destructive nature.

#### 5. Information Contained on Website

In the course of using the Website or Services, users may provide information about themselves, which may be visible to certain other users authorized by the FD/MAS Registry). You understand that by posting materials on the Website or otherwise providing materials to us, you are agreeing to allow us to aggregate your anonymized data or data stripped of a standard set of personal identifiers for use by the community and other third parties. You understand that all information publicly posted or privately transmitted through the Website is the sole responsibility of the person from which such content originated and that the FD/MAS Registry will not be liable for any errors or omissions in any content. You understand that the FD/MAS Registry cannot guarantee the identity of any other users with whom you may interact in the course of using the Website or Services. Additionally, we cannot guarantee the authenticity of any data that users may provide about themselves.

#### 6. Disclaimer of Medical Advice

You understand and acknowledge that all users are responsible for their own medical care, treatment, and oversight. All of the Content provided on the Website, including text, treatments, dosages, outcomes, charts, profiles, graphics, photographs, images, advice, messages, or forum postings, are for informational purposes only and are not intended to be a substitute for independent professional medical judgment, advice, diagnosis, or treatment. The Content is not intended to establish a standard of care to be followed by a user of the Website. You understand and acknowledge that you should always seek the advice of your physician or other qualified health provider with any questions or concerns you may have regarding your health. You also understand and acknowledge that you should never disregard or delay seeking medical advice relating to treatment or standard of care because of information featured on or transmitted through the Website.

#### 7. Disclaimer of Warranties

a. THE WEBSITE AND THE CONTENT MADE AVAILABLE ON THE WEBSITE ARE PROVIDED ON AN "AS IS" AND "AS AVAILABLE" BASIS. THE FD/MAS REGISTRY DOES NOT MAKE ANY EXPRESS OR IMPLIED WARRANTIES, REPRESENTATIONS OR ENDORSEMENTS WHATSOEVER (INCLUDING, BUT NOT LIMITED TO, WARRANTIES OF TITLE OR NON-INFRINGEMENT, OR THE IMPLIED WARRANTIES OF MERCHANTABILITY OR FITNESS FOR A PARTICULAR PURPOSE) WITH REGARD TO THE WEBSITE, THE CONTENT, ANY ADVICE OR SERVICES PROVIDED THROUGH THE WEBSITE OR ON THE INTERNET GENERALLY. SOME STATES MAY NOT PERMIT THE DISCLAIMER OF IMPLIED WARRANTIES, SO THE FOREGOING DISCLAIMER MAY NOT APPLY TO YOU. THE FD/MAS REGISTRY DOES NOT WARRANT THAT THE WEBSITE WILL BE UNINTERRUPTED OR ERROR-FREE OR THAT DEFECTS IN THE WEBSITE WILL BE CORRECTED, THAT ANY INFORMATION CONTAINED ON OR TRANSMITTED THROUGH THE WEBSITE IS COMPLETE, ACCURATE OR CURRENT, THAT USER OR OTHER INFORMATION WILL BE COMPLETELY

SECURE FROM UNAUTHORIZED ACCESS OR DISCLOSURE, OR THAT ANY INFORMATION IS FREE OF VIRUSES OR OTHER ROGUE PROGRAMMING.

#### 8. Limitation of Liability

a. UNDER NO CIRCUMSTANCES SHALL THE FDF OR ANY OF ITS PARTNERS, CONTRIBUTORS, AGENTS, EMPLOYEES, OR ANY OTHER PARTY INVOLVED IN CREATING, PRODUCING, OR DISTRIBUTING THE WEBSITE OR PROVIDING CONTENT, ADVICE, PRODUCTS, OR SERVICES THROUGH THE WEBSITE BE LIABLE FOR ANY DIRECT, INDIRECT, INCIDENTAL, SPECIAL, OR CONSEQUENTIAL DAMAGES FOR LOSS OF PROFITS, GOODWILL, USE, DATA, OR OTHER INTANGIBLE LOSSES (EVEN IF WE HAVE BEEN ADVISED OF THE POSSIBILITY OF SUCH DAMAGES) THAT RESULT FROM: (I) THE USE OF OR INABILITY TO USE THE WEBSITE; (II) ANY INACCURACIES, ERRORS, OMISSIONS, OR LACK OF AUTHENTICITY IN THE CONTENT; (III) USE OF THE CONTENT; (IV) THE COST OF PROCURING SUBSTITUTE MERCHANDISE, ADVICE, AND SERVICES RESULTING FROM USE OF THE WEBSITE; (V) ANY LOSS, MISUSE, OR UNAUTHORIZED ACCESS TO OR ALTERATION OF INFORMATION OR MATERIALS TRANSMITTED TO OR CONTAINED ON THE WEBSITE; (VI) STATEMENTS, ADVICE, WARRANTIES, GUARANTEES, OR CONDUCT OF THE FD/MAS REGISTRY OR ANY THIRD PARTY ON THE WEBSITE, OR (VII) ANY OTHER MATTER RELATING TO THE USE OF THE WEBSITE. YOU HEREBY ACKNOWLEDGE THAT THIS PARAGRAPH SHALL APPLY TO ALL CONTENT, ADVICE, MERCHANDISE, AND SERVICES AVAILABLE THROUGH THE WEBSITE. BECAUSE SOME STATES MAY NOT ALLOW THE EXCLUSION OR LIMITATION OF LIABILITY FOR CONSEQUENTIAL OR INCIDENTAL DAMAGES, IN SUCH STATES LIABILITY IS LIMITED TO THE LEAST AMOUNT PERMITTED BY LAW. THE LIMITATIONS OF LIABILITY PROVIDED IN THIS AGREEMENT INURE TO THE BENEFIT OF THE FD/MAS REGISTRY AND ITS RESPECTIVE AFFILIATES, PARTNERS, CONTRIBUTORS, OFFICERS, DIRECTORS, EMPLOYEES, ASSIGNS, ATTORNEYS, AND AGENTS.

#### 9. Indemnification

You agree to indemnify and otherwise hold harmless the FDF, its officers, employees, agents, subsidiaries, affiliates, and other partners from any and all liability, including any and all direct, indirect, incidental, special, consequential, or exemplary damages, and any and all costs and/or expenses (including reasonable attorneys' fees) resulting from (i) your use of the Website, including, but not limited to, your access to, submission of, or distribution of, information to or from the Website; (ii) any misuse, unauthorized access to, disclosure, alteration, or destruction of the Website, information contained in the Website, and/or your communications with or through the Website, or (iii) any other matter relating to the Website. You understand and agree that the FDF and FD/MAS Registry may disclose information provided if in its good faith belief such disclosure is required by applicable law.

#### 10. Copyright and Copyright Agent

The Website and the compilation (meaning selection, composition, and arrangement) of all of the content on the Website is the exclusive property of the FDF, or used with permission of the owner, and protected by U.S. and international copyright law. The FDF reserves the right to remove any content,

from any source, at any time, for any reason (including, but not limited to, claims or allegations made by third parties relating to such content). Users of the Website agree to not take any action with respect to content of the Website that would violate the intellectual property rights of the FDF or the individual rights of other users. Content contained on, and the intellectual property by which the Website is produced may not be modified, copied, distributed, framed, republished, downloaded, displayed, or sold in any form or by any means, in whole or in part, without the prior written consent of the FDF or, in the case of user-submitted content, any other appropriate party or parties. It is the sole responsibility of the user to secure all necessary rights and permissions before downloading, reproducing, modifying, distributing, or otherwise using user-submitted content.

The FDF respects the intellectual property of others and asks that participants of the FD/MAS Registry do the same. If a user or any other party feels that its work has been copied in a way that constitutes copyright infringement, that person must provide the FD/MAS Registry with the following information:

1.) A physical or electronic signature of a person authorized to act on behalf of the owner of an exclusive right that is allegedly infringed; 2.) Identification of the copyrighted work claimed to have been infringed, or, if multiple copyrighted works at a single online Website are covered by a single notification, a representative list of such works at that Website; 3.) Identification of the material that is claimed to be infringing or to be the subject of infringing activity and that is to be removed or access to which is to be disabled, and information reasonably sufficient to permit the service provider to locate the material; 4.) Information reasonably sufficient to permit the service provider to contact the complaining party, such as an address, telephone number, and, if available, an electronic mail address at which the complaining party may be contacted; 5.) A statement that the complaining party has a good faith belief that use of the material in the manner complained of is not authorized by the copyright owner, its agent, or the law; 6.) A statement that the information in the notification is accurate, and under penalty of perjury, that the complaining party is authorized to act on behalf of the owner of an exclusive right that is allegedly infringed.

Users may contact the FD/MAS Registry for notice of claims of infringement on this Website as follows:

By e-mail: [info@fibrousdysplasia.org](mailto:info@fibrousdysplasia.org)

By mail:

1380 Monroe St. NW. #420

Washington, DC 20010

11. Trademarks

The name FDF, FD/MAS Registry, the FD/MAS Registry logo, and other FDF logos, associated Fibrous Dysplasia Foundations, and names are trademarks of the FDF and associated Fibrous Dysplasia



Foundations. You agree not to display or use these trademarks in any manner without the FDF's prior, written permission. The section titles of these Terms and Conditions are displayed for convenience only and have no legal effect. If any provision of these Terms and Conditions are to be unenforceable for any reason, the remaining provisions will be unaffected and remain in full force and effect.

## 12. International Users

The FD/MAS Registry makes no claims that information on the Website is appropriate or may be downloaded outside of the United States. Access to the Website may not be legal in certain countries or for certain persons. If you access the Website from outside of the United States, you do so voluntarily at your own risk and are responsible for compliance with the laws of your jurisdiction regarding online conduct and acceptable content. User personal information ("Information") that is submitted to this Website will be collected, processed, stored, disclosed, and disposed of in accordance with applicable U.S. law, our Terms and Conditions and our Informed Consent document.

If you are a non-U.S. user, you acknowledge and agree that the FD/MAS Registry may collect and use your Information and disclose it to other entities outside your resident jurisdiction. In addition, such Information may be stored on servers located outside your resident jurisdiction. U.S. law may not provide the degree of protection for Information that is available in other countries. By providing us with your Information, you acknowledge that you consent to the transfer of such Information outside your resident jurisdiction to the U.S. or other jurisdictions with different, and in some cases, lower levels of protection for your Information. If you do not consent to such transfer, you may not use the Website.

## 13. General Practices Regarding Use and Storage.

You agree that the FD/MAS Registry has no responsibility or liability for the deletion or failure to store any messages and other communications or other Content maintained or transmitted by the Website. You acknowledge that the FD/MAS Registry reserves the right to log off accounts that are inactive for an extended period of time. You further acknowledge that the FD/MAS Registry reserves the right to modify these general practices and limits from time to time.

## 14. Termination

You agree that the FD/MAS Registry may, with or without cause, immediately terminate your account and access to the Website or the Services without prior notice. Without limiting the foregoing, the following will lead to a termination by the FD/MAS Registry of a user's use of the Website or the Services (a) breaches or violations of these Terms and Conditions or other incorporated agreements or guidelines, (b) requests by law enforcement or other government agencies, (c) a request by you (self-initiated account deletions), (d) unexpected technical issues or problems, and (e) extended periods of inactivity. You agree that all terminations shall be made in the FD/MAS Registry's sole discretion and

that the FD/MAS Registry shall not be liable to you or any third-party for any termination of your account or access to the Website or the Services.

#### 15. Communications from FD/MAS Registry

From time to time, the FD/MAS Registry or other related entities will notify users of updates and other valuable information about the FD/MAS Registry, the Website and related clinical and research information. By using the Website, or registering or subscribing for services provided on or through the Website, users consent to being contacted by the FD/MAS Registry and related entities, and to receiving such updates and information. Users acknowledge and agree that users must always accept email transmissions from the FD/MAS Registry, in order, to continue to use the Website or the Services.

#### 16. Fees

Signing up for and use of an account to provide information to the FD/MAS Registry is free.

#### 17. Governing Law

Any disputes arising out of the use of the Website or the Services or these Terms and Conditions will be governed by the law of Louisiana regardless of conflict of law principles. Sole and exclusive jurisdiction and venue over any dispute arising out of or relating to these Terms and Conditions shall lie in the appropriate federal or state court in Louisiana.

#### 18. Statute of Limitations

Any cause of action you may have with respect to use of the Website must be commenced within one (1) year after the claim or cause of action arises.

#### 19. Contacting the FD/MAS Registry Coordinator

If you have any medical, research, treatment or patient referral questions, contact a staff member at the FDF home office, [info@fibrousdysplasia.org](mailto:info@fibrousdysplasia.org).

If you have questions about the FD/MAS Registry, or to report violations of these Terms and Conditions, please email the Registry Coordinator at: [registry@fibrousdysplasia.org](mailto:registry@fibrousdysplasia.org).