

Dear Registry Applicant,

Thank you for your interest in the **National Registry of Myotonic Dystrophy and Facioscapulohumeral Muscular Dystrophy Patients and Family Members!** The Registry was established through a contract with the National Institutes of Health to link people with Myotonic Dystrophy and FSHD with researchers who are studying these rare diseases. At this time, we are registering individuals with FSHD and DM, as well as unaffected family members. Therefore, we invite you to encourage other family members to apply.

In this packet, you will find the forms necessary for your **child** to apply to the Registry. To apply, please complete the following steps:

1. There are two identical *Permission Forms* and *Assent Forms*. Please read and sign one of these forms. This signed *Permission* and *Assent Forms* must be returned to us in order for us to review your information. The second *Permission* and *Assent Forms* are for your files.
2. Please complete the *Patient Information Form* and return it to us.
3. Please complete the *Request for Medical Information Form* and return it to us. This form gives us your permission to communicate directly with your **child's** neurologist and/or primary care physician. We would be happy to request your medical records on your behalf once we receive this signed form.
4. Optional: If you would like to communicate with us via email, you must sign an additional consent form, the *Patient Email Consent Form*. This form is optional, but must be completed if you want to use email to communicate with National Registry staff. There are two copies of this form – return one signed copy to us. The second copy is for your files.

For your convenience, we have enclosed a postage paid envelope. Please place all signed forms into this envelope and return the packet to us. Once all your information is received, it will be reviewed carefully. You may receive a phone call or letter from one of the study coordinators to clarify information.

If you have any questions as you complete this process, please do not hesitate to call us. Our toll free number is 1-888-925-4302. Once we have your signed email consent form, you may email us at dystrophy_registry@URMC.rochester.edu.

We sincerely appreciate your willingness to participate in this important endeavor!

Sincerely,

Colleen Donlin-Smith, MA
Sr. Health Project Coordinator

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Health Project Coordinator

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