

**National Registry of Myotonic Dystrophy and Facioscapulohumeral
Muscular Dystrophy Patients and Family Members**



**National Registry for Myotonic Dystrophy and Facioscapulohumeral Muscular
Dystrophy Patients and Family Members**

Assent Form – Affected Child

(For children 12-17 years of age who are able to understand
the procedures involved in the Registry)

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Study Coordinator: James Hilbert, MS
Study Coordinator: Elizabeth Luebbe

This form tells you how to get your name on a list of people who want to help doctors and scientists learn about ways to help people with two muscle diseases, myotonic dystrophy and facioscapulohumeral muscular dystrophy. This list is called a Registry. You are being asked to join because you or somebody in your family has one of these muscle diseases. We want your help. You can ask any questions that you want before deciding if you want to help. If you have any questions you can call (888) 925-4302 or (585) 276-0004 and speak with one of the Health Project Coordinators. We will not put your name in the Registry unless you say we can.

These are the reasons we want you to let us put your name in the Registry:

- To keep track of people with muscle problems.
- To help doctors and scientists find people with muscle problems so that they can learn more about the cause of the problems and develop better treatments.
- To learn more about families that have lots of people with muscle problems.

If you decide to let us put your name and information about you in the Registry, you may be asked at a later time if you would like to help with other projects about these muscle diseases. These projects will be explained to you and you can decide if you would like to help with these projects as well.

On this page, there is a place for you to sign your name if you want to join the Registry. You do not have to sign if you don't want to be in the Registry. Even if your parents say yes, you do not have to. You can change your mind at anytime. If someday you decide you want your name taken off the Registry list, just tell your parents or call us and we will remove your name. No one will be upset with you.

For children 12-17 years of age who are able to understand the Registry procedures:

CHILD'S PRINTED NAME: _____

CHILD'S SIGNATURE: _____

DATE: _____

For Registry Staff Use Only:

REGISTRY COORDINATOR PRINTED NAME: _____

REGISTRY COORDINATOR'S SIGNATURE: _____

DATE: _____

The information for this Registry is collected under the authority of Sections 435-442 of the PHS Act (285d-285d-7 of Title 42, USC). The data will be maintained in accordance with the Privacy Act 42 United States Code 241.

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Page 2 of 2

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For office use only: Name: _____ Registry Number: _____