

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

**Patient Information Form *for Unaffected Blood Relatives of Individuals with Myotonic Dystrophy or Related Diseases***

The purpose of this form is to collect information from individuals who are unaffected blood relatives of individuals who have myotonic dystrophy or a related disease. **Please return this form within three weeks if at all possible.** If you have any questions about this form, please call Local: (585) 506-0004 in Rochester NY or Toll Free: (888) 925-4302 for assistance. You may reach us by Fax at: (585) 273-1255 or by mail at: 601 Elmwood Avenue, Box 673, Rochester, NY 14642-8673.

Date: \_\_\_\_\_

NAME: \_\_\_\_\_  
                    First                                    Middle                                    (Maiden)                                    Last

ADDRESS: \_\_\_\_\_  
                    Street  
  
                    \_\_\_\_\_  
                    City                                    State                                    Zip Code

TELEPHONE: Home: (\_\_\_\_\_) \_\_\_\_\_ Work: (\_\_\_\_\_) \_\_\_\_\_  
                                    Area Code                    Number                                    Area Code                    Number

EMAIL ADDRESS: \_\_\_\_\_

Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_ Sex:  Male  Female  
                    Mo Day Year

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.

This project has been funded in whole or in part by the National Institutes of Health (grant #U54-NS048843 and contracts #N01-AR-5-2274 and #NO1-AR-0-2250).

1. Indicate how many family members are affected:

	YES	NO	If "Yes," how many are affected?
Brothers and sisters			
Children (Are any affected children under the age of 18? <input type="checkbox"/> yes <input type="checkbox"/> no)			
Spouse			
Mother			
Father			
Grandparents			
Aunts or uncles			
Cousins or other relatives			

2. Are any other members of your family in the Registry?

Yes  No  Not sure

3. Have you ever had any of these tests?

Examination by a neurologist  Yes  No  Not sure

Electromyography (EMG, needle inserted into muscles to check electrical activity)  Yes  No  Not sure

Muscle biopsy  Yes  No  Not sure

DNA (blood test)  Yes  No  Not sure

#### ETHNICITY/RACE

Are you Hispanic or Latino?  Yes  No

How would you describe your race? Select one or more of the following categories:

American Indian or Alaskan Native

Asian

Black or African American

White

Native Hawaiian or other Pacific Islander

Please provide the name, address, and telephone number of a family member or friend we can contact in case you move or change your phone number.

Name: \_\_\_\_\_ Relationship: \_\_\_\_\_

Address: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Medical records which confirm your diagnosis must be sent to us for review. Attached is a Request for Information form. If you sign it and return it to us, we can contact your doctor for any test results and they can send them directly to us.

**IMPORTANT:** Please read, sign and return the attached Consent Form. Without it we cannot consider you for entry into the Registry.

Thank you for your support of the National Registry.