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

Patient Information Form ***for Unaffected Blood Relatives of Individuals with Facioscapulohumeral Muscular Dystrophy (FSHD)***

The purpose of this form is to collect information from individuals who are unaffected blood relatives of individuals who have FSHD. **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.

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For office use only. Name: ______________________________ Registry Number: ____________________

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? ☐ yes ☐ 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. Please indicate which of the following statements best represents you:

_____ I do not have any symptoms of FSHD but I have not been examined by a neurologist.

_____ I do not have any symptoms of FSHD and a neurologist has examined me and confirmed that I am not affected.

_____ I had DNA testing that confirmed that I am not affected.

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: _______________________________

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.

For office use only. Name: ___________________________________ Registry Number: ________________________