

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

Patient Information Form *for individuals with
Facioscapulohumeral Muscular Dystrophy(FSHD)*

The purpose of this form is to collect information from 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.

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

<p>Where did you learn about the Registry?</p> <p><input type="checkbox"/> Your doctor <input type="checkbox"/> Internet <input type="checkbox"/> MDA</p> <p><input type="checkbox"/> Family <input type="checkbox"/> Support group <input type="checkbox"/> Magazine/Newsletter</p> <p><input type="checkbox"/> Friend</p> <p><input type="checkbox"/> Other _____</p>

INFORMATION ABOUT YOUR DIAGNOSIS OF FSHD:

1. What was the first symptom of FSHD? _____

2. How old were you when you had your first symptom of FSHD? (Give your best estimate even if you are not sure.) _____ years old.

3. How old were you when your FSHD was diagnosed? (Give your best estimate even if you are not sure.) _____ years old.

4. Did you have 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 test (blood test) for FSHD Yes No Not sure

5. Who made your diagnosis of FSHD? (Check as many as apply)

- primary care physician a neurologist
 family member yourself
 a specialist in a neuromuscular clinic or Muscular Dystrophy Clinic

6. Were you the first person in your family to have the diagnosis of FSHD?
 Yes No Not sure

7.	YES	NO	Not Sure
Is anyone else in your family affected with FSHD? If yes , please indicate with a check in the appropriate boxes below.			
	YES	NO	Number affected
Brothers and sisters			
Children (Are any affected children under the age of 18? <input type="checkbox"/> yes <input type="checkbox"/> no)			
Mother			
Father			
Grandparents			
Aunts or uncles			
Cousins or other relatives			

8. Are any other members of your family in the Registry?
 Yes No Not sure

OCCUPATION AND EMPLOYMENT

What is your current occupation (complete below)

Employed (describe your job)_____

Homemaker Student Retired

Disabled because of FSHD Disabled (not due to FSHD)

Unemployed (not due to disability)

Comments_____

Has FSHD affected your employment? Yes No

If yes, how (check boxes)

Lost job Forced to go on disability

Job modified to accommodate your physical limitations Early retirement

EDUCATION

Highest level of education completed: (check appropriate box)

No formal education College

Grade school Graduate school

High school Other_____

Technical school Don't know

<u>USE OF ASSISTIVE DEVICES</u>			Your age when you started using the device (give your best estimate even if you are not sure).	
	YES	NO		Years old
Use ankle braces				Years old
Use long leg braces				Years old
Use a cane at times				Years old
Use a walker at times				Years old
Use a wheelchair. If yes, circle one: 1. For long distances only 2. Usually 3. Always				Years old
Other_____				Years old

SIGNS AND SYMPTOMS

Are you right or left handed?

Do you have any of the following?	YES	NO
1. Is one arm noticeably more affected by the disease? If yes, which is weaker: <input type="checkbox"/> left <input type="checkbox"/> right		
2. Is one leg noticeably more affected by the disease? If yes, which is weaker: <input type="checkbox"/> left <input type="checkbox"/> right		
3. Have you had surgery to fix your shoulder blades? If yes, which side: <input type="checkbox"/> left <input type="checkbox"/> right <input type="checkbox"/> both		
4. Do you have difficulty breathing? If yes, does your doctor feel it is related to your FSHD?		
Do you require a breathing machine? If yes, which machine do you use: <input type="checkbox"/> BiPAP <input type="checkbox"/> CPAP <input type="checkbox"/> Ventilator		
5. Have you had heart problems? If yes, what type: <input type="checkbox"/> palpitations <input type="checkbox"/> abnormal fast heart rate <input type="checkbox"/> abnormal slow heart rate <input type="checkbox"/> heart failure <input type="checkbox"/> heart attack or angina		
6. Have you been diagnosed with hearing loss? Do you wear a hearing aid?		
7. Have you had any eye problems? (Other than needing glasses or contacts) If yes, check all that apply: <input type="checkbox"/> retinal hemorrhage <input type="checkbox"/> retinal detachment <input type="checkbox"/> Coat's Disease <input type="checkbox"/> other _____		
8. Do you have muscle or joint pain? If yes, check all areas affected: <input type="checkbox"/> neck/upper back <input type="checkbox"/> shoulder/upper arms <input type="checkbox"/> lower back/hips <input type="checkbox"/> elbows <input type="checkbox"/> knees/thighs <input type="checkbox"/> ankles/lower legs		

BROKEN BONES AND SURGERY

Have you ever had a broken bone or operation? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, please list them and the date they occurred. <i>If you need more room, please use an additional piece of paper.</i>	
Broken bone or operation	Year that it occurred

CURRENT ABILITIES AND RESTRICTIONS IN MOVEMENT

To help us understand your current abilities/difficulties, please grade yourself in the following:

Facial Weakness: (Check as many as apply)

- Are your eyes occasionally dry and irritated? Yes No
Are your eyes always dry and irritated? Yes No
Do you have difficulty pronouncing certain words? Yes No
Do you have difficulty swallowing? Yes No
Do you have trouble whistling or drinking through a straw? Yes No

Arm function: Which statement best describes your ability?

(Please check **only one** box.)

- Are you able to raise your arms up sideways over your head?
Are you able to raise your arms sideways but not above shoulder level
but do not need assistance for activities such as combing/shampooing
hair, shaving, applying makeup, brushing teeth, etc.
Are you able to raise your arms sideways but not above shoulder level
but do need assistance for activities such as combing/shampooing
hair, shaving, applying makeup, brushing teeth, etc.
Unable to raise arms sideways

Leg function: Which statements best describe your ability?

(Please check **all that apply**.)

- Walk and run
Walk but not run
Walk and climb stairs without using hand rail or cane
Walk and climb stairs only with the help of railing or cane
Walk with cane/walker but unable to climb stairs
Unable to walk

Mobility/Transfers: Which statement best describes your ability?

(Please check **only one** box.)

When getting up from a chair are you able to:

- Get up without using your arms (ie; with arms folded across your chest)
Need to use your arms to push up from the chair
Use specific maneuvers to get up from a chair
Get up only with the assistance of a person or device

Getting out of bed are you able to:

- Sit up from a lying position in bed without any problems
Sit up from a lying position in bed only by using your arms
Sit up from a lying position in bed only by turning sideways and using
your arms
Sit up from a lying position in bed only with someone's assistance
Transfer from bed to chair only with assistive devices (ie: walker, bed rails)

MEDICATIONS

Do you take medications? Yes No Don't know

If yes, please give the name of each medication. Include both prescription and non-prescription drugs and herbal remedies.

- Codes: 1 Have taken for less than one month
 2 Have taken for one month to one year
 3 Have taken for more than one year

Name of medication	Circle one			Daily Dosage	
	1	2	3	Milligrams/Tablet	Tablets/Day
	1	2	3		
	1	2	3		
	1	2	3		
	1	2	3		
	1	2	3		
	1	2	3		
	1	2	3		
	1	2	3		
	1	2	3		
	1	2	3		

If you need more room, please use an additional piece of paper.

What is your current height: _____ feet _____ inches, and weight: _____ pounds

ALLERGIES

Please list any foods or drugs to which you are allergic:

_____	_____
_____	_____
_____	_____
_____	_____

Do you smoke tobacco? Yes No

TREATMENTS OR COUNSELING

Have you ever received any of the following?

	Yes	No	Not sure
Physical therapy			
Genetic counseling			
Emotional or psychological counseling			
Speech therapy			
Occupational therapy			
Vocational rehabilitation			
Other _____			

OTHER MEDICAL PROBLEMS

Have you ever had or do you have any of these conditions:

<input type="checkbox"/> Diabetes	<input type="checkbox"/> Stroke
<input type="checkbox"/> High blood pressure	<input type="checkbox"/> Kidney trouble
<input type="checkbox"/> Asthma	<input type="checkbox"/> Thyroid trouble
<input type="checkbox"/> Rheumatoid arthritis	<input type="checkbox"/> Stomach ulcers
<input type="checkbox"/> Emphysema	<input type="checkbox"/> Gall bladder trouble
<input type="checkbox"/> Pneumonia	<input type="checkbox"/> Prostate trouble
<input type="checkbox"/> Heart disease or heart beat irregularity	<input type="checkbox"/> Liver trouble
<input type="checkbox"/> Cancer or tumor, type _____	<input type="checkbox"/> Chronic infection
<input type="checkbox"/> High cholesterol	<input type="checkbox"/> Trouble with sexual function
<input type="checkbox"/> Miscarriage	<input type="checkbox"/> Acid reflux or "heartburn"
<input type="checkbox"/> Stillbirth	<input type="checkbox"/> Constipation
<input type="checkbox"/> Psychological problems such as depression or anxiety	
<input type="checkbox"/> Other _____	

ETHNICITY/RACE

Are you Hispanic or Latino? Yes No

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

<input type="checkbox"/> American Indian or Alaskan Native	<input type="checkbox"/> Asian
<input type="checkbox"/> Black or African American	<input type="checkbox"/> White
<input type="checkbox"/> Native Hawaiian or other Pacific Islander	

Have you ever participated in a research study for FSHD ? Yes No Not sure

Have you ever received an experimental treatment for FSHD? Yes No

If yes, what was that treatment: _____

In case you needed help filling out this form, who was your helper? (state below)

Name of individual filling out the form: _____

Relationship to applicant: _____

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 help with the Registry.

Local: (585) 506-0004, Rochester NY

Toll Free: (888) 925-4302

FAX: (585) 273-1255

Address: 601 Elmwood Avenue, Box 673, Rochester, NY 14642-8673

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).