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

Where did you learn about the Registry?

☐ Your doctor ☐ Internet ☐ MDA
☐ Family ☐ Support group ☐ Magazine/Newsletter
☐ Friend
☐ Other_____________________________________

For office use only. Name: ________________________________ Registry Number: ______________________

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? ☐ yes ☐ 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

For office use only. Name: ____ Registry Number: _________________________

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

USE OF ASSISTIVE DEVICES				**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: ☐ left ☐ right		
2. Is one leg noticeably more affected by the disease? **If yes,** which is weaker: ☐ left ☐ right		
3. Have you had surgery to fix your shoulder blades? **If yes,** which side: ☐ left ☐ right ☐ 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: ☐ BiPAP ☐ CPAP ☐ Ventilator		
5. Have you had heart problems? **If yes,** what type: ☐ palpitations ☐ abnormal fast heart rate ☐ abnormal slow heart rate ☐ heart failure ☐ 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: ☐ retinal hemorrhage ☐ retinal detachment ☐ Coat's Disease ☐ other______________________________		
8. Do you have muscle or joint pain? **If yes,** check all areas affected: ☐ neck/upper back ☐ shoulder/upper arms ☐ lower back/hips ☐ elbows ☐ knees/thighs ☐ ankles/lower legs		

BROKEN BONES AND SURGERY

Have you ever had a broken bone or operation? ☐ Yes ☐ No
If yes, please list them and the date they occurred. *If you need more room, please use an additional piece of paper.*

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	
				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:

☐ Diabetes	☐ Stroke
☐ High blood pressure	☐ Kidney trouble
☐ Asthma	☐ Thyroid trouble
☐ Rheumatoid arthritis	☐ Stomach ulcers
☐ Emphysema	☐ Gall bladder trouble
☐ Pneumonia	☐ Prostate trouble
☐ Heart disease or heart beat irregularity	☐ Liver trouble
☐ Cancer or tumor, type____________	☐ Chronic infection
☐ High cholesterol	☐ Trouble with sexual function
☐ Miscarriage	☐ Acid reflux or "heartburn"
☐ Stillbirth	☐ Constipation

☐ Psychological problems such as depression or anxiety

☐ Other_______________________________________

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	

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.

For office use only. Name: ____ Registry 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 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.

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