

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

Patient Information Form *for individuals with Myotonic Dystrophy or Related Diseases*

The purpose of this form is to collect information from 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.

If you have a disease that is related to myotonic dystrophy, such as proximal myotonic myopathy (PROMM) or myotonic dystrophy type 2, please write your diagnosis here _____ and then fill out the form even though all questions may not apply to your condition.

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? | | |
| <input type="checkbox"/> Your doctor | <input type="checkbox"/> Internet | <input type="checkbox"/> MDA |
| <input type="checkbox"/> Family | <input type="checkbox"/> Support group | <input type="checkbox"/> Magazine/Newsletter |
| <input type="checkbox"/> Friend | | |
| <input type="checkbox"/> Other _____ | | |

INFORMATION ABOUT YOUR DIAGNOSIS OF MYOTONIC DYSTROPHY:

1. What was the first symptom of myotonic dystrophy? _____

2. How old were you when you had your first symptom of myotonic dystrophy? (Give your best estimate even if you are not sure.) _____ years old.
3. How old were you when your myotonic dystrophy 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 | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not sure |
| Electromyography (EMG, needle inserted into muscles to check electrical activity) | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not sure |
| Muscle biopsy | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not sure |
| DNA test (blood test) for myotonic dystrophy | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not sure |
5. Who made your diagnosis of myotonic dystrophy? (Check as many as apply)

| | |
|--|--|
| <input type="checkbox"/> primary care physician | <input type="checkbox"/> a neurologist |
| <input type="checkbox"/> family member | <input type="checkbox"/> yourself |
| <input type="checkbox"/> a specialist in a neuromuscular clinic or Muscular Dystrophy Clinic | |
6. Were you the first person in your family to have the diagnosis of myotonic dystrophy?

| | | |
|------------------------------|-----------------------------|-----------------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not sure |
|------------------------------|-----------------------------|-----------------------------------|

| 7. | YES | NO | Not Sure | |
|--|------------|-----------|-----------------|------------------------|
| Is anyone else in your family affected with myotonic dystrophy? If yes , please indicate with a check in the appropriate boxes below. | | | | |
| | YES | NO | Not Sure | Number Affected |
| Brothers and sisters | | | | |
| Children | | | | |
| (If yes, 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?

| | | |
|------------------------------|-----------------------------|-----------------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not sure |
|------------------------------|-----------------------------|-----------------------------------|

SIGNS AND SYMPTOMS

| Do you have any of the following? | | | | Your age when the problem began (give your best estimate even if you are not sure). |
|--|-----|----|----------|---|
| | Yes | No | Not sure | |
| Trouble with your hands/grip locking up, or hand stiffness | | | | |
| Difficulty making a tight fist, loss of grip strength or difficulty opening jars | | | | |
| Trouble speaking clearly | | | | |
| Trouble with swallowing | | | | |
| Weakness of face | | | | |
| Difficulty walking on your toes or heels, or ankle weakness | | | | |
| Difficulty getting up from the floor, rising from a chair, or climbing stairs | | | | |
| Trouble with breathing or shortness of breath | | | | |
| Cataracts | | | | |
| Racing heart beat, irregular heart beat, palpitations, or pacemaker | | | | |
| Baldness | | | | |

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 the back of this form.</i> | |
| Broken bone or operation | Year that it occurred |
| | |
| | |
| | |
| | |
| | |
| | |
| | |

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 the back of this form.

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"/> Child showing signs of myotonic dystrophy within the 1 st four weeks of life | |
| <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 | |

SLEEP PROBLEMS

How likely are you to doze off or fall asleep in the following situations, in contrast to feeling just tired? This refers to your usual way of life in recent times. Even if you have not done some of these things recently try to work out how they would have affected you. Use the following scale to choose the *most appropriate number* for each situation:

- 0 = would *never* doze
- 1 = *slight* chance of dozing
- 2 = *moderate* chance of dozing
- 3 = *high* chance of dozing

| <u>Situation</u> | <u>Chance of dozing</u> |
|---|-------------------------|
| Sitting and reading_____ | _____ |
| Watching TV_____ | _____ |
| Sitting, inactive in a public place (such as a theater or a meeting)_____ | _____ |
| As a passenger in a car for an hour without a break_____ | _____ |
| Lying down to rest in the afternoon when circumstances permit_____ | _____ |
| Sitting and talking to someone_____ | _____ |
| Sitting quietly after lunch without alcohol_____ | _____ |
| In a car, while stopped a few minutes in traffic_____ | _____ |

Have you ever participated in a research study for myotonic dystrophy ?

Yes No Not sure

Have you ever received an experimental treatment for myotonic dystrophy?

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.

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