

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

Where are the members located?

The Registry members are located in almost every state. We have members with DM living in 48 states and members with FSHD in 46 states.

The table below represents the geographic location of Registry members.

Region	DM (%)	FSHD (%)
Northeast	32	28
Midwest	24	26
South	27	26
West	17	19

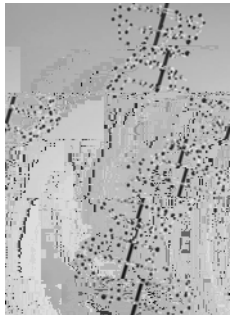
How many applications have been sent? How many people are enrolled?

	DM	FSHD
Applications sent	915	845
Applications returned	583 (64%)	538 (64%)
Enrolled subjects	465	409
Affected adults	409	348
Affected child	23	8
Unaffected family	33	53

Besides muscle problems, what are some other medical issues affecting Registry members?

Problem	DM (%)	FSHD (%)
Acid reflux	36	24
Constipation	36	22
Gallbladder	18	6
Heart disease	18	13
Pneumonia	24	16

What other information can be presented?



The Registry has collected genetic (DNA) information from almost half of its members. DNA is the genetic material responsible for such things as eye color, hair color, and other more complex traits. This information is not required for entry into the Registry, but it can help researchers anonymously study various medical problems of these rare diseases. Other information that can be reported includes muscle problems, the use of assistive devices (braces, wheelchairs, etc), medications, and employment characteristics.

How can enrolled Registry members continue to help?

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Membership Survey regarding the National Registry's Website: www.dystrophyregistry.org

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| 1. | Have you visited the Registry's website? | Yes | No |
| 2. | If you answered "Yes" to Question 1, do you check the website periodically for updates? | Yes | No |
| 3. | Do you have any suggestions for improving the site? | Yes | No |