

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

601 Elmwood Avenue, Box 673. Rochester, NY 14642

**Investigator Application**

**Title of Project:**

**Principal Investigator (Name, title, institution, address, phone, email address):**

**Contact Information (Send correspondence to: Name, title, institution, address, phone, email address):**

**Funding Source:**

**Type of Assistance Requested:**  Subject Recruitment  Anonymous Data

Please attach study protocol in the following format (1 inch margins, 12 font):

1. Summary (not to exceed 1/2 page)
2. Hypothesis/specific aims (1 page)
3. Background and preliminary data (not to exceed 3 pages)
4. Experimental design
  - a. Subjects: inclusion/exclusion criteria
  - b. Protocol methods
  - c. Statistical methods and power calculations
5. IRB or WIRB approval letter
6. Statement of why recruitment through the National Registry would be beneficial
7. Lay explanation of the protocol for mailing to potential participants from the National Registry.

Upon approval you will be required to submit a letter of intent agreeing to:

1. Work with the Registry data manager to generate a list of eligible participants to be contacted by the Registry coordinators.
2. Have subjects notify the Registry if further information related to their muscle disease is found during participation in a Registry approved investigation so that the Registry database can be updated.
3. Notify us of the number of Registry members participating in the study.
4. Cite the Registry in any publications.

(Continued)

Please mail the application packet to Liz Luebbe. If you have questions, please contact one of the Registry Staff below.

Liz Luebbe  
Elizabeth\_Luebbe@urmc.rochester.edu  
Health Project Coordinator  
585-275-7867

Jim Hilbert, MS  
James\_Hilbert@urmc.rochester.edu  
Health Project Coordinator  
585-273-5590

Signature of Principal Investigator: \_\_\_\_\_ Date: \_\_\_\_\_