



### Research Subject E-mail Consent Form

Subject name:  
Subject #:  
Subject e-mail:  
Researcher: Dr. Rabi Tawil  
Researcher e-mail: dystrophy\_registry@urmc.rochester.edu  
Authorized representative:  
Name: \_\_\_\_\_  
Relationship: \_\_\_\_\_  
E-Mail: \_\_\_\_\_

- f) The subject should not use e-mail for communication regarding sensitive medical information.
- g) It is the subject's responsibility to follow up and/or schedule an appointment if warranted.
- h) Recommended uses of subject-to-researcher e-mail should be limited to:
  - a. Appointment requests
  - b. Prescription refills
  - c. Requests for information
  - d. Updates to information or exchange of non-critical information such as laboratory values.

#### 1. RISK OF USING E-MAIL

Transmitting subject information by e-mail has a number of risks that subjects should consider. These include, but are not limited to, the following:

- a) E-mail can be circulated, forwarded, stored electronically and on paper, and broadcast to unintended recipients.
- b) E-mail senders can easily misaddress an e-mail.
- c) Backup copies of e-mail may exist even after the sender or the recipient has deleted his or her copy.
- d) Employers and on-line services have a right to inspect e-mail transmitted through their systems.
- e) E-mail can be intercepted, altered, forwarded, or used without authorization or detection.
- f) E-mail can be used to introduce viruses into computer systems.

#### 2. CONDITIONS FOR THE USE OF E-MAIL

The researcher cannot guarantee but will use reasonable means to maintain security and confidentiality of e-mail information sent and received. The subject and researcher must consent to the following conditions:

- a) E-mail is not appropriate for urgent or emergency situations. The researcher cannot guarantee that any particular e-mail will be read and responded to.
- b) E-mail must be concise. The subject should schedule an appointment if the issue is too complex or sensitive to discuss via e-mail.
- c) E-mail communications between subject and researcher will be filed in the subject's research record.
- d) The subject's messages may also be delegated to any member of the study team for response.
- e) The researcher will not forward subject-identifiable e-mails outside of URM and Affiliates without the subject's prior written consent, except as authorized or required by law.

#### 3. INSTRUCTIONS

To communicate by e-mail, the subject shall:

- a) Avoid use of his/her employer's computer.
- b) Put the subject's name in the body of the e-mail.
- c) Put the topic (e.g., study question) in the subject line.
- d) Inform the researcher of changes in the subject's e-mail address.
- e) Take precautions to preserve the confidentiality of e-mail.
- f) Contact the researcher's office via conventional communication methods (phone, fax, etc.) if the subject does not receive a reply within a reasonable period of time.

#### 4. SUBJECT ACKNOWLEDGMENT AND AGREEMENT

I acknowledge that I have read and fully understand this consent form. I understand the risks associated with the communication of e-mail between the researcher and me. I consent to the conditions and instructions outlined here, as well as any other instructions that the researcher may impose to communicate with me by e-mail. I agree to use only the pre-designated e-mail address specified above. Any questions I may have had were answered.

\_\_\_\_\_  
Subject or Authorized Representative signature

Date

\_\_\_\_\_  
Researcher signature

Date