

INFORMATION SHEET

A Patient-Focused Survey to Assess the Effects of the COVID-19 Pandemic on Patients with Muscular Dystrophy

Principal Investigator: Rabi Tawil, MD

This form describes a research study that is being conducted by Rabi Tawil, MD from the University of Rochester's Department of Neurology. The purpose of this study is to understand the effects of the COVID-19 pandemic, and the social policies in place to control the pandemic, on people with muscular dystrophy.

If you decide to take part in this study, you will be asked to complete one survey that will take about 20 minutes. The survey will ask questions about your diagnosis, how COVID-19 may affect your condition and the care you receive, and about your perceived stress during the pandemic. We estimate that approximately 1500 subjects will take part in this study.

Some of the survey questions may be upsetting or make you feel uncomfortable. You can skip any of the questions you do not want to answer. All of the information we collect will be stored in a secure manner and only study team members will have access to it. There are no other expected risks. There are also no expected benefits.

You will not be paid for participating in this study. There will be no cost to you to participate in this study.

The University of Rochester makes every effort to keep the information collected from you private. In order to do so, we will de-identify your data. The data will be stored in a database housed at the University of Rochester. Access to the database is restricted by Active Directory Domain permission given only to study personnel and is managed by the University of Rochester's Neurology Information Technology.

We will use the survey to conduct the study. We will keep the information we collect indefinitely.

Your participation in this study is completely voluntary. You are free not to participate at any time, for whatever reason. No matter what decision you make, there will be no penalty or loss of benefits to which you are otherwise entitled. However, as

the surveys are de-identified, we will not be able to remove your data once the survey is complete.

For more information or questions about this research you may call Rabi Tawil, MD at 585-275-6372. Please contact the University of Rochester Research Subjects Review Board at 265 Crittenden Blvd., CU 420628, Rochester, NY 14642, Telephone (585) 276-0005 or (877) 449-4441 [insert country code (001) if applicable] for the following reasons:

- You wish to talk to someone other than the research staff about your rights as a research subject;
- To voice concerns about the research;
- To provide input concerning the research process;
- In the event the study staff could not be reached.