

**To be conducted at
The University of Texas Southwestern Medical Center**

Who is conducting the study?

Dr. Salman Bhai an assistant professor at University of Texas Southwestern Medical Center is conducting this study.

What is the purpose of the research?

To understand patient reported outcomes in myositis. This study is being done to understand how myositis affects other aspects of life such as your emotional and mental wellbeing and that of your caregiver. We will ask about how myositis affects your social life, pain, fatigue, and financial wellbeing. We will also ask about your myositis journey related to diagnosis and management.

Who is asked to participate?

Patients with myositis and caregivers of patients with myositis.

Do you have to be in this study?

You do not have to participate if you don't want to. You may also leave the study at any time. If you decide to stop taking part in this research study, it will not affect your relationship with the UT Southwestern staff or doctors. Whether you participate or not will have no effect on your legal rights or the quality of your health care. If you are a medical student, fellow, faculty, or staff at the Medical Center, your status will not be affected in any way.

What are the Research Procedures?

A REDCap survey will be used primarily using PROMIS surveys that will then be sent out through the Myositis Support and Understanding group's (MSU) listserv of participants. Participants can partake in the survey or not. All patients who complete the survey will be assessed.

What are the Risks and Benefits?

There is a risk of breach of confidentiality as participants will be contacted via email through MSU's listserv. To minimize any risk, the link to the survey can be accessed anonymously and the surveys will be submitted anonymously.

There is a risk of emotional difficulty from recounting your experiences with myositis while taking the survey. To minimize this risk, the participant can voluntarily leave the survey at any time without consequence.

You may not receive any personal benefits from being in this study. We hope the information learned from this study will benefit other people with similar conditions in the future.

Costs and Compensation

There is no cost nor compensation for participating on the study.

Confidentiality

Information we learn about you in this study will be handled in a confidential manner. Your information will be de-identified and it will be kept in a password protected computer with institutional firewall and the data will only be accessed by the study team. If we publish the results of the study in a scientific journal or book, we will not identify you.

Any data collected as part of this study may be used for future research studies without your consent. Any information that identifies you will be removed before it is used for future research studies.

Contact Information for questions or comments:

The University of Texas Southwestern Medical Center Human Research Protection Program (HRPP) oversees research on human subjects. HRPP and Institutional Review Board (IRB) representatives will answer any questions about your rights as a research subject, and take any concerns, comments or complaints you may wish to offer. You can contact the HRPP by calling the office at 214-648-3060.

Before you agree to participate, make sure you have read (or been read) the information provided above; your questions have been answered to your satisfaction; and you have freely decided to participate in this research.

This form is yours to keep.