Who can I contact if I have questions, complaints, wish to withdraw or have other concerns about the Musculoskeletal Outcomes Registry?

Please contact:
Dr. Charles Saltzman, Chair
Department of Orthopaedics
801-587-5404

Being in this research registry is voluntary; withdrawal will not affect your medical care.
WHAT IS THE MUSCULOSKELETAL OUTCOMES REGISTRY?

A “registry” is a data system designed to collect, manage, and analyze information on people with certain medical problems. The University of Utah’s Musculoskeletal Outcomes Registry will help your providers improve patient care by allowing them to analyze your treatment outcomes. Major advances have been made in musculoskeletal research both nationally and internationally through the information collected from registries. We hope that this registry will do the same for our patients.

WHAT DATA GOES INTO THE REGISTRY?

As part of your routine medical care, we collect data about your health, your functional abilities, life circumstances, education and other relevant information. Your doctor will use this information to help guide your care. Using this information, doctors hope to improve the outcome of the medical or surgical care we are currently offering.

WHERE IS THE DATA KEPT?

The information you provide about your health is securely stored in University of Utah Health Care computer databases. Only your healthcare team and researchers with security clearance have access to the data.

Additionally, your personal health information may be disclosed to local or national registries as part of an effort to monitor specific musculoskeletal conditions in the general public. This information could include your name, medical record number, date-of-birth, and your social security number. This information is needed to allow these registries to track your condition long-term. The information gathered by these registries will help in the quality improvement efforts of musculoskeletal providers both locally and nationally. This information will be encrypted and secured to protect your privacy.

WHAT CAN YOU DO TO HELP?

You are providing valuable information for this study just by being a patient at the University of Utah Hospitals and Clinics. You may also help by allowing us to contact you in the future for further follow-up and to confirm your contact information. In general, these contacts are done once a year. Your contact information will be stored in a secure databank here at the University of Utah.

HOW WILL THIS BENEFIT YOU?

Being in this registry will not directly benefit you. However, we hope that information from the registry may benefit others in the future by identifying best care practices.

IS THERE ANY RISK?

There is the possible risk of loss of confidentiality (e.g. inadvertent disclosure of study data, etc.).

HOW DO RESEARCHERS USE THE REGISTRY?

This study has been approved by the University’s Institutional Review Board and the information collected from this registry will be used for quality improvement purposes. The Institutional Review Board is a review board specifically charged with protecting the rights and welfare of people involved in research. The information may also be used for presentations and publications. Your personal health information will be removed from all presentations and publications.

CAN I WITHDRAW FROM THE REGISTRY?

Your information is automatically included in this registry, however, you have the right to have your information removed from the registry. Refusal to participate or the decision to withdraw from this study will involve no penalty or loss of benefits to which you are otherwise entitled. If you don’t take part, you will receive all standard care that is available to you. You can withdraw from the registry at any point in time. If you have decided to “opt out” of the registry we will no longer include your information in the registry for analysis. If you wish to opt out of this registry please contact Dr. Charles Saltzman at 801-587-5404 or the clinical research coordinator at 801-213-3442. It is possible that you will continue to receive phone calls as part of your standard of care.

WHO DO I CONTACT WITH QUESTIONS ABOUT MY RIGHT AS A RESEARCH PARTICIPANT

Contact the Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at irb@hsc.utah.edu.