

The University of Texas Southwestern Medical Center at
Dallas Texas Scottish Rite Hospital for Children

**Authorization for Use and Disclosure of
Health Information for Research
Purposes**

NAME OF RESEARCH PARTICIPANT: _____

What is the purpose of this form?

This authorization describes how information about you and your health will be used and shared by the researcher(s) when you participate in the research study: "Multicenter Prospective Cohort Study on Current Treatments of Legg-Calve-Perthes Disease," a research database of prospectively identified patients with Legg-Calve-Perthes Disease ("Research Project"). Health information is considered "protected health information" when it may directly identify you as an individual. By signing this form you are agreeing to permit the researchers and others (described in detail below) to have access to and share this information. If you have questions, please ask a member of the research team.

Who will be able to use or share my health information?

Texas Scottish Rite Hospital for Children may use or share your health information with other investigators ("Researchers") for the purpose of this research study.

Will my protected health information be shared with someone other than the Researchers? Yes, the Researchers may share your health information with others who may be working with the Researchers on the Research Project ("Recipients") for purposes directly related to the conduct of this research study or as required by law. These other people or entities include:

- The UT Southwestern Institutional Review Board (IRB). This is a group of people who are responsible for assuring that the rights of participants in research are respected. Members and staff of the IRB at UT Southwestern may review the records of your participation in this research. A representative of the IRB may contact you for information about your experience with this research. If you do not want to answer their questions you may refuse to do so.
- Collaborating Institutions: There will be other future research facilities who will work with Texas Scottish Rite Hospital for Children on the Research Project.
- Representatives of domestic and foreign governmental and regulatory agencies may be granted direct access to your health information for oversight, compliance activities, and determination of approval for new medicines, devices, or procedures.

Medical information collected during this study and the results of any test or procedure that may affect your medical care may be included in your medical record. The information included in your medical record will be available to health care providers and authorized persons including your insurance company.

How will my health information be protected?

Whenever possible your health information will be kept confidential as required by law. Federal privacy laws may not apply to other institutions, companies or agencies collaborating with UT Southwestern on this research project. There is a risk that the Recipients could share your information with other without your permission. UT Southwestern cannot guarantee the confidentiality of your health information after it has been shared with the recipients.

Medical information collected during this study and the results of any test or procedure that may affect your medical record will be available to health care providers and authorized persons including your insurance company.

Why is my personal contact being used?

Your personal contact information is important for the UT Southwestern Medical Center research team to contact you during the study. However, your personal contact information will not be released without your permission.

What health information will be collected, used and shared (disclosed)?

The Researchers will collect:

- Age/Date of Birth
- Gender
- Ethnicity
- Height/weight/BMI
- Birth weight
- Date of first symptoms
- Date of diagnosis
- Date of radiographic studies
- Age at skeletal maturity
- Results of contrast-enhanced MR imaging
- PROMIS Questionnaire
- Date of first TSRHC Orthopaedic Clinic visit
- Dates of contrast-enhanced MRIs
- Clinical data
- Surgical data
- Family history
- History of maternal smoking
- Concomitant illnesses or disorders
- History of corticosteroid therapy
- History of trauma
- Results of radiographic studies

Will my health information be used in a research report?

Yes, the research team may fill out a research report. (This is sometimes called "a case report".) The research report will not include your name, address, or telephone or social security number. The research report may include your date of birth, initials, dates you received medical care and a tracking code. The research report will also include information the research team collects for the study.

Will my health information be used for other purposes?

Yes, the Researchers and Recipients may use your health information to create research data that does not identify you. Research data that does not identify you may be used and shared by the Researchers and Recipients in a publication about the results of the Research Project or for other research purposes not related to the Research Project.

Do I have to sign this authorization?

No, this authorization is voluntary. Your health care providers will continue to provide you with healthcare services even if you choose not to sign this authorization. However, if you choose not to sign this authorization, you cannot take part in this Research Project.

How long will my permission last?

This authorization has no expiration date. You may cancel this authorization at any time. If you decide to cancel this authorization, you will no longer be able to take part in the Research Project. The Researchers may still use and share the health information that they have already collected before you canceled the authorization. To cancel this authorization, you must make this request in writing to: Harry K.W. Kim, MD, 2222 Welborn Street, Dallas, Texas 75219, 214-559-5000.

Will I receive a copy of this authorization?

Yes, a copy of this authorization will be provided to you.

Signatures:

By signing this document you are permitting UT Southwestern Medical Center to use and disclose health information about you for research purposes as described above .

Signature of Research Participant

Date

AM/PM Time

For Legal Representatives of Research Participants (if applicable):

Printed Name of Legal Representative:

Relationship to Research Participant: _____

I certify that I have the legal authority under applicable law to make this Authorization on behalf of the Research Participant identified above. The basis for this legal authority is:

(e.g., parent, legal guardian, person with legal power of attorney, etc.)

Signature of Legal Representative

Date

AM/PM Time