

Natural History of OI Study

Study Name "The Longitudinal Study of Osteogenesis Imperfecta"
Eligibility Children and adults with a diagnosis of OI; all ages and all severities

Description **What is a Natural History of OI Study?**
"The Longitudinal Study of Osteogenesis Imperfecta" is a natural history study. It will collect and analyze information about the health of people who have OI. To be successful, this study must include as many people as possible and include children and adults of all ages from infancy through senior citizen and all types of OI from the mildest to the most severe. Our goal is to enroll 500 people. Each study center will be collecting exactly the same type of health information in the same way from all participants. This information is then entered into the LCRC secure, anonymous, central database.

Study Information

Study participants are required to visit the Linked Center once a year for 5 years. Each person will be asked for a detailed medical history and receive an extensive annual physical exam including various diagnostic studies such as a DEXA. Participating in this natural history study does not replace a person's regular health care team and does not interfere with any other research studies he or she may already be enrolled in.

What does participating mean to people who have OI?

This is an important opportunity to contribute to an important study. Enrollment of children with OI in a Natural History study is important to the participating children because it can reveal treatable problems early. Enrollment of adults as well as children in this kind of study will help uncover issues previously not known to be associated with OI about living with OI across a life time and about long term affects of different treatments. A longitudinal natural history study, one that goes for 5 years or more, helps to identify areas that need more detailed research and sets priorities for future studies.

Contact Information for all Study Sites

For detailed information about participating, please speak with a study coordinator at one of the following sites.

Baylor Medical Center, Houston, TX

Contact Person: Mary Mullins, RN
Phone Number: 832-822-4263 or 1-800-364-5437 ext. 24263
Email: mullins@bcm.edu
Enrolling children and adults with OI; all ages; all types

Kennedy Krieger Institute, Baltimore, MD / DuPont Hospital for Children, Wilmington, DE

Contact Person: Pamela Melvin, RN
Phone Number: 443-923-2707
Email: Melvin@kennedykrieger.org
Enrolling children and adults with OI; all ages; all types
In partnership with the KKI, the DuPont Hospital for Children in Wilmington, DE will begin enrolling children later in 2010; contact information for the Wilmington, DE location will be provided at that time.

Oregon Health & Science University / Portland Shriners Hospital, Portland, OR

Contact Person: Jessica Adsit, MS
Phone Number: 503-418-5882

Email: Adsit@ohsu.edu

Enrolling children and adults with OI; all ages; all types

National Institutes of Health, Bethesda, MD

Contact Person: Catherine Reisenberg, FNP, PhD

Phone Number: 301-496-0741

Email: oiprogram@mail.nih.gov

Enrolling children with OI types III and IV; follow-up offered into young adulthood

Shriners Hospital for Children, Chicago, IL

Contact person: Angela Caudill, MPT

Phone Number: 773-622-5400 EXT. 5271

Email: acaudill@shrinenet.org

Enrolling children and adults with OI; all ages; all types

Shriners Hospital for Children, Montreal, Quebec Canada

Contact information will be provided as soon as possible.

Children and adults with OI; all ages; all types will be eligible