

## Longitudinal Study of OI

- Sponsor:** The Rare Diseases Clinical Research Network, Brittle Bone Disorders Consortium
- Eligibility:** Children and adults with a diagnosis of OI; all ages, all types, and all degrees of severity  
1000 participants are needed.
- Goal:** To improve the health and quality of life of people with OI
- Description:** The Longitudinal Study of OI can be described as a natural history study. It will collect and analyze information about the health of people of all ages and all types of OI over an extended period of time. This phase of the study builds on the information from the first phase of the study started through the Osteogenesis Imperfecta Foundation's Linked Clinical Research Centers. A natural history study seeks to uncover how OI changes across the life span, match up features of OI with the genetic causes, and track the long term effects of different treatments.
- Studies:** During this phase of the Longitudinal Study information on compression fractures of the spine, scoliosis, pregnancy and dental health will be gathered in addition to general health and bone health information.
- Centers:** This is a multi-center study with 7 participating centers in the United States and 1 in Canada. Each of the centers will see children and adults. For detailed information about participating, contact the study coordinator at one of the sites. Contact information for all of the sites is listed below. **People who were enrolled in the Longitudinal Study of OI through the OI Foundation's Linked Clinical Research Centers Program are encouraged to re-enroll.** All of the former LCRC sites are part of the expanded study. Contact information for each site:

### Site Information:

Baylor College of Medicine, Houston, TX  
Principal Investigator: V. Reid Sutton, MD  
Contact: Mary Mullins, RN. Phone: 832-822-4263; Email: [mullins@bcm.edu](mailto:mullins@bcm.edu)

Shriners Hospital for Children, Montreal, Canada  
Principal Investigator: Frank Rauch, MD; Francis Glorieux, MD  
Contact: Michaela Durigova. Phone 514-282-7158

Oregon Health and Science University, Portland, OR  
Principal Investigator: Eric Orwoll, MD  
Contact: Melanie Abrahamson. Phone: 503-494-7480; Email: [Orwoll@ohsu.edu](mailto:Orwoll@ohsu.edu)

Hospital for Special Surgery, New York, NY  
Principal Investigator: Cathleen Raggio, MD  
Contact: Sobiah Khan. Phone 212-774-2355; Email: [khans@hss.edu](mailto:khans@hss.edu)

Shriners Hospital for Children, Chicago, IL  
Principal Investigator: Peter Smith, MD  
Contact: Angela Caudill, MPT. Phone: 773-385-5868; Email: [acaudill@shrinenet.org](mailto:acaudill@shrinenet.org)

Children's Hospital and Medical Center/University of Nebraska Medical Center, Omaha, NE  
Principal Investigator: Paul Esposito, MD  
Contact: Elizabeth Strudthoff. Phone: 402 - 559 - 0681; Email: [elizabeth.strudthoff@unmc.edu](mailto:elizabeth.strudthoff@unmc.edu)

University of California Los Angeles/Orthopedic Institute for Children/Shriners Hospital for Children, Los Angeles, CA  
Principal Investigator: Deborah Krakow, MD  
Contact: Samantha Alon. Phone: 310-794-6420; Email: [Salon@mednet.ucla.edu](mailto:Salon@mednet.ucla.edu)

Children's National Health System, Washington, DC  
Principal Investigator: Laura Tosi, MD  
Contact: Marianne Floor. Phone 210-320-2157; Email: [mfloor@childrensnational.org](mailto:mfloor@childrensnational.org)