

# Brittle Bone Disorders (BBD) Consortium

 [consortiapedia.fastercures.org/consortia/brittle-bone-disorders-bbd-consortium/](http://consortiapedia.fastercures.org/consortia/brittle-bone-disorders-bbd-consortium/)

## Research Areas



### Tool Development

Resource



### Biomarker Research

Genomic Biomarker

## At a Glance

- Status: **Active Consortium**
- Year Launched: **2014**
- Initiating Organization: **NIH Rare Disease Clinical Research Network**
- Initiator Type: **Government**
- **Rare** disease
- Location: **North America**

## Abstract

Baylor College of Medicine was selected by the National Institutes of Health (National Institute of Arthritis and Musculoskeletal and Skin Disease, National Institute of Dental and Craniofacial Research, National Center for Advancing Translational Sciences, and National Institute of Child Health and Human Development) to lead the Brittle Bone Disorders Rare Disease Clinical Research Consortium, a multi-center initiative that focuses on understanding and providing better treatment options for rare diseases characterized by bone fragility and fractures.

## Mission

The mission of the Brittle Bone Disorders Consortium is to conduct clinical research and clinical trials to learn more about the disease. It is a group of physicians, researchers, and educators focused on learning more about osteogenesis imperfecta (OI) and developing new and better treatments to improve the care of patients with OI. It also seeks to provide up-to-date information for patients to help them manage their diseases and to assist in connecting patients with support groups, expert doctors, and clinical research opportunities.

The goals of the Brittle Bone Disorders Consortium are as follows:

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## Structure & Governance

This consortium is part of the Rare Diseases Clinical Research Network (RDCRN), an initiative of the Office of Rare Diseases Research, National Center for Advancing Translational Sciences (NCATS). The RDCRN is designed to advance medical research on rare diseases by providing support for clinical studies and facilitating collaboration, study enrollment, and data sharing. Through the RDCRN consortia, physician scientists and their multidisciplinary teams work together with patient advocacy groups to study more than 200 rare diseases at sites across the nation.

Funding and scientific oversight for the RDCRN are provided by NCATS and 10 National Institutes of Health components: Eunice Kennedy Shriver National Institute of Child Health and Human Development; the National Cancer Institute; National Heart, Lung and Blood Institute; National Institute of Allergy and Infectious Diseases; National Institute of Arthritis and Musculoskeletal and Skin Diseases; National Institute of Dental and Craniofacial Research; National Institute of Diabetes and Digestive and Kidney Diseases; National Institute of Mental Health; National Institute of Neurological Disorders and Stroke; and Office of the Director. In addition, patient advocacy groups provide funds for many of the projects.

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## Patent Engagement

The RDCRN BBD Contact Registry is a way for patients with brittle bone disorders and their family members to learn about BBD research studies they may be able to join. Participation is completely voluntary, and participants can withdraw at any time. There is no cost to join the Contact Registry.

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## Impact/Accomplishment

The consortium's Clinical Project 1 is a longitudinal study of OI. There are more than 13 genetic disorders that contribute to the spectrum of OI. There is great need to understand the natural histories of these conditions as correlated to genotype as these disorders are being defined by their underlying

molecular etiologies.

The consortium will:

## Links/Social Media Feed

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Homepage

<http://www.rarediseasesnetwork.org/cms/BBD>

## Points of Contact

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## Sponsors & Partners

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Baylor College of Medicine

Children's National Medical Center

Hospital for Special Surgery

Kennedy Krieger Institute/Hugo W. Moser Research Institute

Oregon Health and Science University

Osteogenesis Imperfecta Foundation

Shriner's Hospital for Children, Chicago/Marquette University

Shriner's Hospital for Children, Montreal

University of California Los Angeles

University of South Florida

University of Washington

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Updated: **04/07/2016**