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# Osteogenesis Imperfecta

## Research Program at the National Institutes of Health

The National Institutes of Health (NIH) is seeking children and adults with osteogenesis imperfecta (OI) to join a study to learn more about the natural history of OI from childhood to adulthood and identify genes that play a role in the disease. This study is a part of the NIH Osteogenesis Imperfecta Translational Research Program, led by physician scientist, Joan Marini, M.D., Ph.D. The program has provided comprehensive care for children with OI for more than 30 years, while conducting clinical and laboratory research.

### Eligible participants are:

- Children with OI up to the age of 12  
OR
- People with OI of any age who were previously seen at NIH as children

### Study details:

- Children will visit every 3 to 4 months, up to age 5, then every 6 to 12 months.
- Adult participants will visit every 6 to 12 months.
- Visits may last a few days.
- No cost for study-related tests or procedures.
- Travel within the U.S. and accommodations will be reimbursed.
- Participants may have DXA bone density, X-rays, heart and hearing tests, dental exam, rehabilitation and physical therapy evaluations, pulmonary function tests, CT imaging and MRI of the head, neck and lungs, kidney ultrasound, blood work, and genetic testing.
- Clinical results can be provided to participant.

*The NIH Clinical Center, America's Research Hospital in Bethesda, MD  
(in the Washington, DC metro area).*

**NIH Clinical Center Office of Patient Recruitment**

**1-800-411-1222** (refer to #18-CH-0120)

TTY for the deaf or hard of hearing: 1-866-411-1010

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