

Osteogenesis Imperfecta Clinic at Kennedy Krieger Institute

Who We Are

The Osteogenesis Imperfecta (OI) Clinic at Kennedy Krieger Institute is a nationally recognized leader in the evaluation, treatment, and research for individuals with osteogenesis imperfecta or other related genetic disorders. Affecting an estimated 25,000 to 50,000 people in the United States alone, OI is often referred to as “brittle bone” disease. Those who have it are far more susceptible to fractures than the average person. The wide estimate is due to the fact that many with this disorder go undiagnosed.

Who We Serve

We provide expert care for children and adults with a wide range of severity in OI. Our patients include those who are completely ambulatory as well as those who rely entirely on a wheelchair for mobility.

Our Team

Our clinic includes an interdisciplinary team of health-care professionals who are trained and experienced in treating and managing those with OI. This interdisciplinary approach is specifically designed to care for OI patients with myriad medical needs and complexities.

We provide a comprehensive evaluation to ensure a thorough examination of each patient’s unique needs. Our core team includes:

- An **endocrinologist**, who assesses each patient’s medical status and makes treatment and medication recommendations.
- An **orthopedic surgeon**, who determines surgical needs and performs corrective surgery when necessary.
- A **radiologist** to measure bone density.
- A **physical therapist**, who offers therapeutic interventions and assists with mobility issues and daily living activities.

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“The physicians and staff are extremely knowledgeable. They are always available to address my questions, concerns, and review tests completed at my local hospital. The care I’ve received from everyone there is exemplary.”

—Kathy Kowis, OI clinic patient

We are all born with great potential.
Shouldn’t we all have the chance to achieve it?



Kennedy Krieger Institute

For more information, visit www.kennedykrieger.org or call 888-554-2080.

- A **physiatrist** to assess the need for improving function and offer recommendations for bracing, therapies, and exercises.

Kennedy Krieger also has many other professionals who can assist patients based on their individual needs. These include:

- Audiologists to test for hearing loss, which is common in OI.
- Nutritionists to make dietary recommendations designed to maximize bone density.
- Orthotics specialists to fit patients with braces.
- Social workers, who are also available to help patients and families to cope with an OI diagnosis.
- Consultation service team to work with patients' local physicians to develop treatment plans.

Our Approach

Osteogenesis imperfecta varies dramatically in severity, so our treatment model emphasizes unique therapy regimens tailored to each patient.

When patients first arrive in our clinic, they receive a thorough evaluation by several physicians and therapists. Depending on individual need, further care may range from a one-time consultation, routine follow-up care, or care on an as-needed basis. Most choose to receive continuous follow-up care.

Although there is no cure for OI, quality care ensures the best quality of life and the most comfort possible. Despite the obstacles they face, many individuals enjoy productive and fulfilling lives well into adulthood, given the proper treatment. Our approaches include:

- Physical therapy and safe exercises such as swimming.
- Casts, splints, or wraps for broken bones.
- Braces to support legs, ankles, knees, and wrists
- Orthopedic surgery, which may include rods implanted to support the long bones in arms or legs.
- Medications (such as bisphosphonates, teriparatide, calcium, or vitamin D) to strengthen bones.
- Mobility aids, such as canes, walkers, or wheelchairs, as well as other equipment to compensate for weakness or short stature and help increase independence.

Our Research

In addition to state-of-the-art care, our program is also one of the world's premier research centers for the disorder. Current research projects focus on improving current treatments and learning more about how certain changes in the body affect the course of OI, including projects that:

- Explore how certain drugs help increase bone density.
- Examine the effects of diet on bone stability in children with OI.

Working in collaboration with the Osteogenesis Imperfecta Foundation, Kennedy Krieger developed the first OI Registry, a database designed to encourage research by consolidating information and connecting people for specific studies and projects. The registry also increases public awareness of OI, which is often poorly understood in the general community. To learn more about the registry, visit www.osteogenesisimperfecta.org/oir.

Contact Information

Osteogenesis Imperfecta Clinic

For more information or to schedule an appointment, please call 443-923-9400 or toll-free at 888-554-2080. Maryland Relay 711

www.osteogenesisimperfecta.org

Physicians and Healthcare Professionals

Healthcare professionals wishing to refer a patient should call our Physician Referral Line at 443-923-9403.

Clinic Location

801 North Broadway
Baltimore, Md. 21205

Mailing Address

707 North Broadway
Baltimore, Md. 21205



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