

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 OI research, and in the evaluation and treatment of individuals with OI and other related genetic disorders. OI is often referred to as “brittle bone disease”—those who have it are far more susceptible to fractures than the average person. OI affects an estimated 25,000 to 50,000 people in the U.S.; the wide estimate is due to the likelihood 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 healthcare professionals trained and experienced in treating and managing individuals with OI. This interdisciplinary approach is specifically designed to care for patients with OI who have 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:

- A genetic physician, who assesses each patient’s medical status and makes treatment and medication recommendations (such as for oral and intravenous bisphosphonates)
- 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
- A pain management specialist to provide pain management services for patients with fractures and/or in postsurgical care
- A physiatrist, who assesses the need for improvement in functioning and offers recommendations for bracing, therapies and exercises



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

These include:

- Audiologists to test for hearing loss, which is common in OI
- Orthotics specialists to fit patients with braces
- A consultation service team to work with patients’ local physicians to develop treatment plans

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



Kennedy Krieger Institute
UNLOCKING POTENTIAL

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 a physician. Depending on individual need, further care may range from a one-time consultation to routine follow-up care, including 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 possible quality of life and the most comfort possible. Despite the obstacles individuals with OI face, many are able to enjoy productive and fulfilling lives well into adulthood, given proper care and treatment.



Treatment services offered at the clinic include the following:

- Biochemical testing
- Genetic analysis and counseling
- Growth parameters
- Referrals for bone densitometry, a noninvasive technique that measures bone density
- State-of-the-art treatment aimed at increasing bone density and decreasing fractures
- X-rays, as required for diagnosis and treatment

Our Research

The clinic's team has a long and successful record of clinical and basic science research pertaining to OI, including studies on treatment options, clinical characteristics and genetics.

Kennedy Krieger is a member of the Brittle Bone Disorders Consortium, and is one of 14 clinical sites across the country focused on learning more about OI and developing new and better treatments to improve care for individuals with OI. As part of the consortium, we collect clinical data that will both assist in the genetic understanding of OI and expand treatment options.

Additionally, the clinic is studying risk factors and effective treatments for pain in individuals with OI, developing an advanced bone model incorporating OI mutations to better understand OI, and developing methods for personalizing treatments for OI.

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

– Kathy Kowis, patient of the Osteogenesis Imperfecta Clinic

Contact Information

Osteogenesis Imperfecta Clinic at Kennedy Krieger Institute

For more information or to schedule an appointment, please call **443-923-2703**, or call toll-free at **888-554-2080**. TTY users, please contact us at **443-923-2645**, or dial **711** to make a Maryland Relay call.

KennedyKrieger.org/OI

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

Clinic Days and Hours

Monday, Wednesday, Friday
8 a.m. to 3 p.m.

Mailing Address

707 North Broadway
Baltimore, MD 21205

Kennedy Krieger Institute recognizes and respects the rights of patients and their families and treats them with courtesy and dignity. Kennedy Krieger Institute provides care that preserves cultural, psychosocial, spiritual and personal values, beliefs and preferences. Care is free from discrimination based on age, race, ethnicity, religion, culture, language, physical or mental disability, socioeconomic status, sex, sexual orientation, and gender identity or expression, including transgender. We encourage patients and families to become active partners in their care by asking questions, seeking resources and advocating for the services and support they need. © 2020 Kennedy Krieger Institute 03/2020



Learn More. Get Involved. Stay Connected. Visit **KennedyKrieger.org/Connect**

