

Osteogenesis Imperfecta Clinic at Kennedy Krieger Institute

707 North Broadway • Baltimore, Maryland 21205

443-923-9400 • www.kennedykrieger.org

Dear Colleague:

Brittle bone disease—clinically referred to as osteogenesis imperfecta (OI)—affects between 25,000 and 50,000 individuals across the United States. If that sounds like an extremely wide estimate, it is. Unfortunately, patients with this disorder often go undiagnosed, particularly those with less severe forms of OI.

For patients diagnosed with OI, it's imperative to find comprehensive care not only as children, but into adulthood. Unfortunately, finding physicians who specialize in treating it can be a challenge, particularly once patients outgrow their pediatric practitioners. Meanwhile, even those patients with mild forms of the disorder continue to experience many of the same symptoms and complaints, including:

- Higher susceptibility to fracture
- Musculoskeletal pain
- Hearing loss
- Back pain
- Degenerative joint disease.

Here in the Bone and Osteogenesis Imperfecta Department at Kennedy Krieger Institute, we have years of experience treating brittle bone disease in patients throughout their lives, from childhood into adulthood. Our interdisciplinary team of physicians and therapists (listed below) are experts at caring for adults with OI and provide the best possible support for patients with complex clinical problems.

Many OI patients undergo procedures as children that require lifelong maintenance—such as the insertion of femur or tibia rods. Joint replacement is being considered more frequently in the OI adult, and recently, our group has seen several patients with aortic dilatation, mitral or aortic valve insufficiency, and arterial (carotid or common iliac) dissection.

Children with OI grow into adults with OI. These patients still have questions. They still face risks associated with bone fractures, and they still want to discuss treatment options. We understand that our patients' needs don't stop at adulthood—and neither does our dedication to them. For more information about our program, referrals, or scheduling, please call our Physician Referral Line at 443-923-9403.

Sincerely,

Jay R. Shapiro, MD
Director

Simon Mears, MD
Orthopedics

Daniel Judge, MD
Cardiology

Duke Cameron, MD
Cardiac Surgery

Paul Sponseller, MD
Orthopedics

R. Samuel Mayer, MD
Physical Medicine and Rehabilitation

Emily Germain-Lee, MD
Associate Director

Phillip Neubauer, MD
Orthopedics

Joseph Pillion, PhD
Audiology

Jean-Paul Wolinsky, MD
Neurosurgery

Kristin Brockmeyer-Stubbs, MS
Occupational Therapy



Kennedy Krieger Institute