

# OSTEOGENESIS IMPERFECTA

## Background

Osteogenesis Imperfecta (OI) is a rare, genetic bone disorder affecting bone formation. OI, also known as “brittle bone disease,” is characterized by bones that easily fracture or break, often from little to nonapparent stress or injury. OI is caused by a genetic mutation in the gene responsible for producing collagen; a protein that plays an important role in providing structure and strength. As a collagen related disease, lung and cardiac function, muscle strength, ligament flexibility, and dentition (teeth) may also be affected.

OI is generally subdivided into various types. OI Type 1 is the mildest form but occurs most frequently. Bones are prone to fracture, normally spiral fracture with minimal bone deformity, that often occur before puberty. Signs and symptoms include:

- Fracture
- Dislocation
- Bruising
- Muscle weakness
- Loose joints
- Scoliosis
- Hearing loss

Unique facial characteristics are also linked to OI. This can include:

- Distinct blue or gray coloration of the sclera of the eyes
- Mildly triangular-shaped face
- Brittle teeth

Monitoring pain and injury should occur timely and includes assessment of swelling, bruising, tenderness, or limited movement. Reducing occurrence of injury or fracture could also include assessment of joint laxity, muscle strength, spinal curvature, and muscle spasms.

There is no cure for OI. Medications prescribed to treat OI include bisphosphonates to increase bone mineral density. Other treatments include vitamin D and calcium supplements, pain management, and supplemental oxygen for lung issues.



A multidisciplinary treatment approach aims to prevent symptoms, develop muscle, strengthen bone mass and maximize independence. Fracture care is like any other fracture with splinting, casting, and bracing for bone stabilization and healing. For some fractures, surgical rod placement in long bones or “rodding” can be used to help with positioning and to strengthen and prevent fractures.

## Top Takeaways for School Considerations

Osteogenesis imperfecta (OI) is a genetic bone disease characterized by bones that easily fracture or break, often for seemingly no reason.

It is important to be trained to implement recommended precautions, restrictions, and staff response to injury or suspected fracture.

Changes in the student’s behavior could possibly indicate an injury or fracture. The school nurse should be notified to assess the student.

Hearing loss is associated with OI. Classroom accommodations such as preferential seating, reduced background noise, and use of supplementary visual aids should be considered.

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## Kennedy Krieger Institute’s Specialized Health Needs Interagency Collaboration

The Specialized Health Needs Interagency Collaboration (SHNIC) program is a collaborative partnership between Kennedy Krieger Institute and the Maryland State Department of Education.



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## Considerations for the Individualized Healthcare Plan (IHP)

- Nursing diagnosis of risk for injury, pain (acute/chronic) and impaired physical mobility
- Current diagnosed health condition including date of diagnosis, progress of disease process and other chronic health conditions
- Current medication and treatment orders (consider schedule, equipment needs and side effects)
- Use of specialized equipment, adaptive equipment, and orthotics
- Activity, positioning, transferring (consider precautions and/or restrictions)
- Consider emergency care plan(s) (ECP) and emergency evacuation plan(s) (EEP) as related to medical needs in the school setting, and staff education/training, as appropriate

## Discussion Starters for Educational Team

1. Has the school staff been trained to implement the student-specific emergency plan?
2. Would the student benefit from evaluations or assessments in any of the following areas: physical therapy, occupational therapy, speech and language therapy, assistive technology, adapted physical education, functional behavior, psychology, hearing and vision?
3. Would the student benefit from additional academic support and/or modified education (e.g., copies of notes, extra time, reduced workload, simplified instructions, alternative formats for presentation of material, 504/IEP)?
4. Does the student require activity precautions to prevent injury?
5. Is the physical school environment safely accessible for the student's mobility needs (e.g., entry and exit, ramps, location of classes, access to elevator, doorways)?
6. Does the classroom environment support the student's needs and/or equipment (e.g., desk/seating options, maneuverability space, electrical outlets, flash pass for bathroom or nurse)?

## Resources

Kennedy Krieger Institute: Osteogenesis Imperfecta Clinic  
[kennedykrieger.org](http://kennedykrieger.org)

Brittle Bone Society: Information for schools  
[brittlebone.org/information-resources/information-for-schools/](http://brittlebone.org/information-resources/information-for-schools/)

Osteogenesis Imperfecta Foundation  
[oif.org/](http://oif.org/)



Scan QR code or visit  
[KennedyKrieger.org/HealthInformation](http://KennedyKrieger.org/HealthInformation) for more information.