



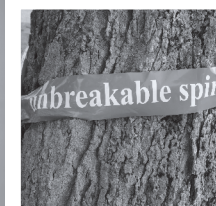
Mission Statement

The Foundation's mission is to improve the quality of life for individuals affected by OI through research to find treatments and a cure, education, awareness, and mutual support.

Osteogenesis Imperfecta

Osteogenesis Imperfecta (OI) is a genetic disorder that makes bones very fragile. About 1/3 of the children diagnosed with OI each year are born into families with no previous history of brittle bones. Most cases involve a defect in type 1 collagen – the protein “scaffolding” of bone and other connective tissues. People with OI have a faulty gene that instructs their bodies to make either too little type 1 collagen or poor quality type 1 collagen. Other cases of OI are caused by mutations in different but related genes. The result, regardless of the cause, is bones that break easily and numerous other connective tissue

symptoms. OI occurs equally in males and females and occurs in all racial and ethnic groups. It is estimated that approximately 50,000 people in the United States have OI. There are several “types” of OI, representing a wide variation in appearance and severity. A person with a mild form of OI might only experience a handful of fractures in their lifetime while those with more severe forms might experience hundreds of fractures and suffer from numerous complications.



OI does not compromise intellectual ability and people with OI succeed in school and the workplace, develop satisfying social and family relationships and live independently. Many people with OI must, however, face challenges – limited mobility and physical pain, lack of access to medical and social services, societal prejudices, and architectural barriers.



804 West Diamond Avenue, Suite 210
Gaithersburg, MD 20878

(844) 889-7579 or (301) 947-0083
Fax: (301) 947-0456

Email: bonelink@oif.org
www.oif.org

People who have OI can experience hundreds of broken bones in a lifetime.



Osteogenesis Imperfecta Foundation

In 1968, Gemma Geisman, a young mother, wrote an article that was published in *Redbook* magazine about her 11-year-old son, Mike, who was living with OI. She wrote

about the challenges they faced as a family, including the isolation and the frightening lack of information or support for caring for a child with a rare fragile bone condition. Letters started flooding her mailbox. Within months, a concerned group of parents joined together to support each other and in 1970 formed the OI Foundation.

Today, the OI Foundation is the only national voluntary health agency dedicated to helping people cope with the problems associated with osteogenesis imperfecta. Each year the Foundation serves thousands of people and provides almost \$1 million in funding to deserving programs and scientists. The Foundation's mission is focused on funding research to find treatments and a cure for OI, as well as to educate, inform, support, and raise awareness about OI. The OI Foundation continues to grow and has volunteers actively supporting the mission in every state.

Goals of the Foundation

One of the cornerstones of the OI Foundation's mission is research. Each year, the Foundation supports OI research through the Michael Geisman Fellowships, annual OIF scientific meetings for medical professionals, and by advocating for increased federal funding for OI research. Our goal is always to expand knowledge about OI, help find new treatments for people living with OI and, of course, one day find a cure.

The OI Foundation is also a part of the National Institutes of Health's Brittle Bone Disorders Consortium (BBDC), serving as the patient advocacy group. In its capacity, it is the bridge between patients, medical professionals, and the investigating researchers for the BBDC. This multi-center program focuses on understanding better treatment options across the lifespan, conducting clinical research, and developing tools to train medical professionals.

The OI Foundation is committed to providing accurate, up-to-date and medically verified information about OI. In addition to responding to more than 7,000 requests for information each year, the Foundation produces and distributes several information resources for both medical professionals and people living with OI. Resources include; books and pamphlets, topic-specific fact sheets, monthly podcast lectures from OI experts, and monthly newsletters. The Foundation's website, www.oif.org, provides valuable information and encourages members of the OI community to connect to support networks – in person and online.



The Foundation's key educational event is the biennial National Conference, which provides the OI community with medical information, research updates, and resources for practical living. It's also an excellent way to develop a network for personal support: to meet new friends and reconnect with old ones!

Increasing awareness about OI is very important to moving the mission of the Foundation forward. Foundation volunteers across the country hold support group meetings, fundraisers, and other events to raise awareness about the important work being done on behalf of people with OI. They also participate in the Foundation's national advocacy program to make lawmakers aware of the importance of funding research into rare disorders, including OI.

How You Can Help

The Osteogenesis Imperfecta Foundation depends on the support of a caring community to continue funding cutting edge research that will someday find a cure for OI. The Foundation encourages your support in the following ways:

- Make your gift at www.oif.org
- Participate in OI events held in your area
- Encourage your co-workers to contribute to the Foundation through the United Way or Combined Federal Campaign (CFC #11334)
- Start a local OI Support Group

**For more information
on how you can help
the OI Foundation,
contact the development staff
at 844-889-7579
or development@oif.org.**

www.oif.org



**OSTEOGENESIS
IMPERFECTA**
OI
FOUNDATION
Unbreakable Spirit®