

WHAT WE DO AT IOIF:

While there has been a lack of understanding and support for many people affected by rare diseases, our trust has taken the mammoth responsibility of educating the society about OI. We intend to bring more empathy and awareness and better independent lifestyle of individuals affected by OI.

Our focus is to empower individuals with OI and other similar rare genetic disorders.

We plan on achieving our goals by:

- Providing financial assistance for individuals with OI who'd like to pursue education.
- Creating a network of committed Orthopedic doctors and surgeons who will guide and provide quality medical services.
- Integrating natural ways to improve the quality of life of an individual with OI by guiding them with gentle Yoga practices, use of Herbal-Ayurvedic and Homeopathic treatments.
- Creating a network of pharmaceutical companies and retail stores to provide medicines and other devices used for treatment of fractures such as splints, metal rods, wheel chairs, braces, crutches etc. at an affordable and discounted price.
- Providing mental health support including counseling to individuals affected by OI and their immediate family members.
- Creating a community support group to meet and exchange notes and learn from each other's experiences.
- Creating a comprehensive database of people affected with OI.
- Educating and keep everyone informed through newsletters.
- Providing a platform to encourage the socio cultural development of OI individuals and to nurture their talents.
- Conducting research in the area of medical and social aspects of OI.
- Providing vocational and soft skills training.
- Creating an awareness and sensitizing the public about Osteogenesis Imperfecta (OI).

JOIN HANDS WITH US BY:

- 1) Referring OI patients to us.
- 2) Supporting education of students with OI.
- 3) Volunteering to raise awareness about OI.
- 4) Sponsoring treatments for OI patients.
- 5) Connecting compassionate orthopaedic doctors/surgeons with us.
- 6) Organising awareness sessions in your communities and schools.
- 7) Donate for the organisation's expenses such as educational material, honorarium for organising workshops, seminars related to OI.

'While the bones might break easily, the spirits never will!'



Indian Osteogenesis Imperfecta Foundation (IOIF)

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OSTEOGENESIS IMPERFECTA (OI)

THE BRITTLE
BONES DISEASE

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WHAT IS OSTEOGENESIS IMPERFECTA?

Osteogenesis Imperfecta or commonly known as OI is a rare genetic disorder that is characterised by fragile bones. It is also known as the 'Brittle Bones Disease'.

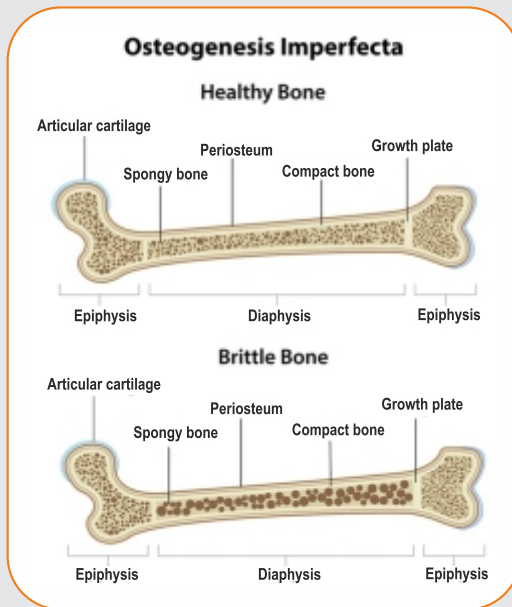
The severity of OI can vary from mild to severe categorized by Type 1 through Type 8.

The milder the condition is, fewer the fractures in the affected person's life time. In severe cases it can involve hundreds of fractures that can occur without any apparent reason.

Although there is plenty of research, a cure has not been found for OI.

Below are a few recommendations commonly followed for a healthier lifestyle with OI.

- 1) Physical and Occupational therapy
- 2) Low impact exercises
- 3) Surgical procedures such as rodding
- 4) Medication and
- 5) Lifestyle modification



INDIAN OSTEOGENESIS IMPERFECTA FOUNDATION (IOIF)

- Indian Osteogenesis Imperfecta Foundation (IOIF) is a charitable foundation to support people with a rare genetic disorder called OSTEOGENESIS IMPERFECTA (OI). It's a condition in which the bones get fragile due to lack of collagen.
- Our aim at IOIF is to raise public awareness about this congenital disorder and strive towards the betterment of the quality of life for those suffering.
- IOIF works towards creating a database and a support system for the patients and their families.
- A society is a mixture of people with a variety of health requirements. Educating the community to propel individuals with limitations to live a dignified equal opportunity productive lifestyle is the larger goal of our trust!
- OI is real and can affect anyone! It doesn't consider caste, creed or the sex of the individual.
- IOIF will use all its resources to help each other to rise up to unimaginable heights!

OUR TEAM

Archana Ravindra Palahalli, Founder Trustee / President - was born with OI. Due to lack of awareness and education and support on Rare Diseases, decided to create OI foundation with like minded people. Even though she has had OI since birth it has not stopped her from having a very normal, active and fulfilling lifestyle. Her life time dream has been to empower individuals with rare diseases so they too can have a productive lifestyle and contribute positively to the community.

Prasad Kuppa, Secretary - joins IOIF with many years of active Social work and currently is working with Qualcomm India Pvt. Ltd. as Director of Engineering.

Dr. Prashanth Inna, Treasurer - is a paediatric orthopaedic surgeon at Manipal Hospital, Bangalore. Having treated the patients with OI and having understood their problems, Dr. Inna has come forward to offer comprehensive services to the OI community besides medical care.

LIFE WITH OI

Living with OI is a life with responsibility of oneself with limited choices.

There is a serious lack of awareness of this condition among general population causing fewer support groups in the community for exchange of knowledge.

Daily life is demanding for the patient as well as for the members of the family. The care needed for an OIer is like the care of a glass doll.

Being cautious and making the home and work environment accident proof consciously at all times can be draining in the beginning but becomes more of a second nature over time. A gentle fall or slip could land the OI patient in cast for 6 weeks or more. Families with an OI patient learn to anticipate and plan lives on a daily basis avoiding potential hazards and make living and work places accident proof as much as possible.

While physical health is visible, the effects of mental, emotional and psychological well-being can have a huge bearing on the immediate members of the family. The sudden surge in the financial drain in the family also affects the members in many unexpected ways.

Diagnosis of OI takes time when affected by a milder form. Family members are unaware of the reasons behind the recurring fractures. In more severe types, surviving through the neonatal period and into the adult life with multiple fractures is a long journey with much pain and drain. Most OI suffering individuals have short stature, limb and spine deformities.

Irrespective of the type or severity, having OI would mean restricted mobility and a huge amount of acceptance of many limitations for a lifetime.

While there is no cure for OI, there are treatments to contain the effects of the disease by following the strict precautionary lifestyle.

With the daily struggles, most people with OI persevere life with a passion to live it to the fullest! Along the way they achieve the unthinkable and establish themselves as productive community members portraying their strong resilience to minor setbacks and being role models for many.