

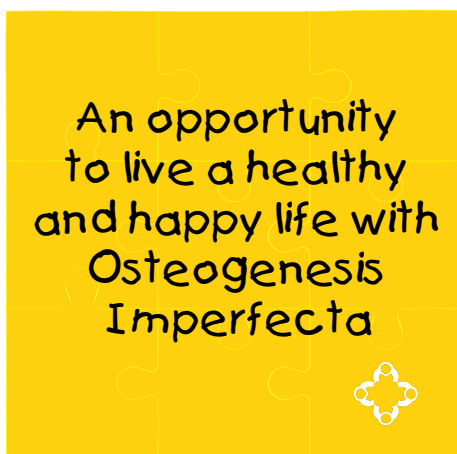
What are the Rights of the Child Living with Osteogenesis Imperfecta (OI)?

All children around the world have equal rights. These rights are declared by the United Nations Convention on the Rights of the Child (UNCRC) 1989. The international community has obligations to ensure no child is deprived of his or her rights, including access to health care services.

The United Nations declares all children must be fully prepared to live an individual life in society and brought up in the spirit of happiness, love, understanding, peace, dignity, tolerance, freedom, equality, and solidarity.

The World Health Organisation states all children, including those living with OI, have the right to “the highest attainable standard of health” and wellbeing without discrimination. This right includes access to facilities for the treatment of illness and rehabilitation.

Children, young people and their families living with OI and other chronic health conditions ask for help with five key action areas (CLAN's Five Pillars). UNCRC recognises these needs as the rights of all children.



What do families and young people living with OI ask for?

Rights and responsibilities under the United Nations Convention on the Rights of the Child (UNCRC)

"We need affordable access to medicine and equipment"



- The inherent right to life (Article 6).
- Governments recognise that a child living with a disability will enjoy a full and decent life in conditions which ensure dignity, promote self-reliance, and facilitate active participation in the community ... and ensure equal access to health and rehabilitation services (Article 23).
- The right to the enjoyment of the highest attainable standard of health and wellbeing without discrimination, and facilities including the provision of necessary medical assistance and health care (Article 24).

"We need more education, research and advocacy"



- The right to express your views and be heard in judicial and administration proceedings that affect your rights (Article 12).
- The right to information and material that promote physical health and mental wellbeing, and safeguards that protect you from information and material that is injurious to your wellbeing (Article 17).
- The right to be informed, have equal access to education, and be supported in the use of knowledge of child health and nutrition (Article 24).
- The right to education that facilitates equal opportunity and experiences and ensure that all children with disability can fulfill their potential as equal citizens (Article 29).
- Governments will make sure everyone understands your rights and that all rights are provided as equal opportunities and experiences that ensure all children, and their families can fulfill their potentials as equal citizens (Article 42).

"All kids need access to good quality health care"



- Governments will ... ensure the development of institutions, facilities and services for your care (Article 18).
- Children who have disability will receive special care and support so that they can live a full and independent life ... with opportunities and experiences that ensure all children and their families can fulfill their potentials as equal citizens (Article 23).
- The right to a standard of living adequate for your physical, mental, spiritual, moral, and social development... including through material assistance and support programs (Article 27).



#OsteogenesisImperfecta
#WBD
#DisabilityRights

#OI
#EVERYchild
#HumanRights

#WishboneDay
#LeaveNoChildBehind
#ChildRights

What do families and young people living with OI ask for?

Rights and responsibilities under the United Nations Convention on the Rights of the Child (UNCRC)

"Family support group meetings help us a lot"



- Governments will respect the rights and responsibilities of families, extended families, and communities to guide children so that, as they grow up, they learn to use their rights properly (Article 5).
- Children have the right to meet with other children and young people and to join groups and organisations (Article 15).
- Children who have disability will receive special care and support so that they can live a full and independent life... with opportunities and experiences that ensure all children, and their families can fulfill their potentials as equal citizens (Article 23).
- Children have the right to rest and leisure, to engage in play and recreational activities (Article 31).

"We are poor - my family needs financial independence"



- Governments will make all rights available to children and their families (Articles 4).
- Children have the right to benefit from social security, including social insurance (Article 26).
- The right to a standard living adequate for your physical, mental, spiritual, moral, and social development (Article 27).
- All children have the right to education without discrimination (Article 28).



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VORD
Vietnamese Organization
for Rare Diseases

www.rarediseases.vn



www.intpedendo.org

CLAN (Caring & Living As Neighbours) is an Australian non-government organisation committed to equity for children and young people living with OI and other non-communicable diseases (NCDs) in low- and middle-income countries (LMICs). Families CLAN works with consistently request collaborative focus around five key pillars to help their children enjoy the highest quality of life possible. These five pillars are the intellectual property of CLAN.

Further information about CLAN's community development approach is available at www.clanchildhealth.org.

For more information on the United Nations Convention on the Rights of the Child (UNCRC) please visit www.unicef.org/crc

References: Ragen, J. (2022) The Risk of Good Intentions: Navigating outcomes for people with disability. Sydney University. Sydney, Australia.

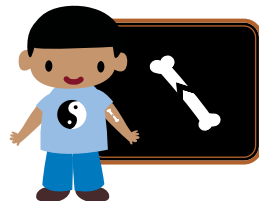
Wishy Logo on this document is credited to Wishbone Day. The image is available at www.wishboneday.com

What you need to know about Osteogenesis Imperfecta (OI)



OI is a group of genetic disorders that affect the production of collagen in the body.

Most people with OI have bones that break, or fracture easily – which is why OI is sometimes called “brittle bones”.



There are different types of OI with symptoms ranging from mild to severe. Genetic mutations associated with OI affect collagen throughout the body, including bones, eyes, ears, joints, teeth, and skin. Children can live happy, healthy and active lives with OI.

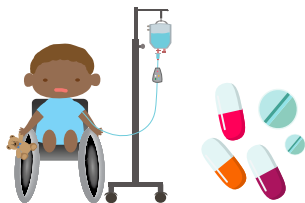


Access to allied health services such as physiotherapy and occupational therapy can help with: increasing freedom of movement; building muscle strength; improving joint mobility; recovery from injury; learning about injury prevention, and safe performance of daily activities.



Sometimes children living with OI need assistive devices such as wheelchairs, braces, and walkers.

These can help children enjoy freedom and independence.



Sometimes children living with OI need access to medication such as bisphosphonates. These can help strengthen bones and prevent injuries. Children with OI can experience pain. Access to fracture care and pain management can help. Access to these medications when needed can improve health and wellbeing.

WORLD WISHBONE DAY - 6 MAY
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Strong support groups can help children and families by fostering a spirit of happiness, understanding, dignity, tolerance, freedom and equality.

Wishbone Day is celebrated every year on 6th May to raise awareness of OI and connect OI communities around the world!