Linked Clinical Research Centers

Osteogenesis imperfecta (OI)

Osteogenesis imperfecta (OI) is a genetic disorder characterized by bones that break easily. For example, a cough or sneeze can break a rib, rolling over can break a leg. There are at least four distinct forms of OI, representing extreme variations in severity and affecting 20,000-50,000 people in the United States. Additional symptoms may include loss of hearing, brittle teeth, short stature, skeletal deformities, or respiratory difficulties.

The OI Foundation

The Osteogenesis Imperfecta Foundation was founded in 1970 as a national network of volunteers hosting support groups for people with osteogenesis imperfecta (OI) and their families. The Foundation's dual purpose of funding research to find treatments and a cure and providing support to help people with OI and their families cope with daily life, continues to shape our vision. The mission of the Osteogenesis Imperfecta Foundation, Inc. is to improve the quality of life for people with osteogenesis imperfecta, through research to find treatments and a cure, education, awareness, and mutual support.

Research improves quality of life for people with OI.

The Problem

When a child is diagnosed with OI, the family is thrown into crisis. Because of OI's rarity, medical professionals often have little to offer in the way of resources, expectations, and treatment and care procedures, such as how to safely hold an infant with OI.

Finding candidates for clinical trials and collecting data on natural history of OI in order to establish standards of care is not possible, due to the limited size of the OI population. The largest OI clinic sees an average of 40 patients per year, most physicians see only one or two patients.

Planning Phase

The National Institutes of Health recommended that the OI Foundation and Children's Brittle Bone Foundation bring the research and clinical community together to create the infrastructure. The Foundations are uniquely positioned to develop this program.

The Foundations developed a request for proposals to locate a Linked Clinical Research Centers Director and project design.

The Foundations worked jointly to coordinate a Steering Committee to review proposals and further develop the project.

The Solution

To speed the pace of research and improve patient care, the OI Foundation and the Children's Brittle Bone Foundation developed the Linked Clinical Research Centers (LCRC) project. The LCRC involves a group of more than 20 Centers governed by a coordinating committee and linked through a central database.

An annual research conference will involve all clinic directors in collaborative activities to ensure information is shared. Training will be provided to existing Centers and potential Centers.

The LCRCs will work together to:

- Define the natural history of OI
- Recruit patients for participation in clinical studies
- Develop standards of care
- Develop a mutation database to identify potential drug therapy and responses
- Develop an X-ray database to assess surgical outcomes
- Integrate research to find treatments and a cure into the routine care at each center

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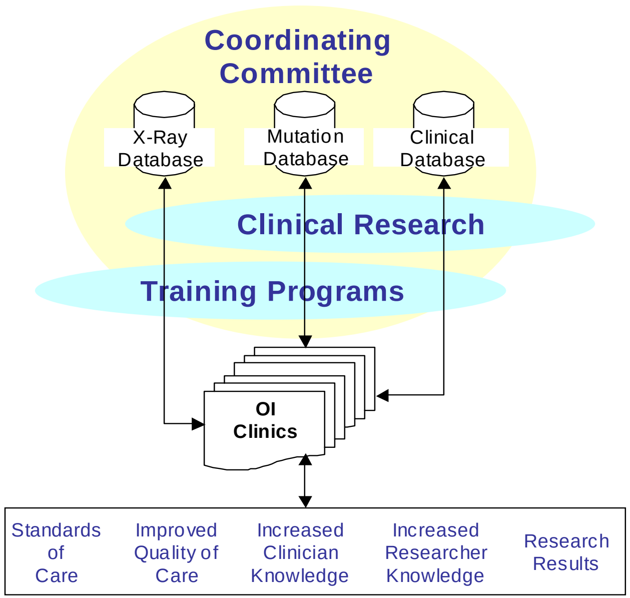

The Result

Improved care for people with OI
and a more focused, collaborative research program
to find better treatments and a cure for OI.

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For further information

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