The Osteogenesis Imperfecta Foundation

Osteogenesis Imperfecta is a genetic disorder affecting the bones and connective tissue of approximately 30-50,000 people in the U.S. Finding candidates for clinical trials and collecting data on the natural history of OI in order to establish standards of care has been problematic, due to the limited size of the population. The largest OI clinic sees an average of 40 patients per year, most physicians see only one or two. To speed the pace of research and improve patient care, the OI Foundation, a patient advocacy group, developed the *Linked Clinical Research Centers* project, a group of twenty clinical centers governed by a coordinating committee and linked through a central database. The OI Foundation is the only organization able to bring together the top researchers and clinicians for this collaborative effort.

The LCRCs will work together to: define the natural history of OI; recruit patients for participation in clinical studies; develop a mutation database to identify potential drug therapy and responses, and; integrate research to find treatments and a cure into the routine care at each center. A central registry for people with OI and a centralized radiographic and imaging center are also included in the LCRC project. An annual research conference will involve all clinic members, including collaborative activities to ensure information is shared, and training for medical professionals to improve patient care. The end result will be improved care for OI patients and a more focused, collaborative research program to find better treatments and a cure for OI.

Presented by: Heller Ann Shapiro, Executive Director, Osteogenesis Imperfecta Foundation, Gaithersburg, MD. www.oif.org