

## 15<sup>th</sup> Annual OI Foundation Scientific Meeting Lay Language Summary

The OI Foundation held its annual Scientific Meeting April 16-17, 2015 in Chicago, IL. Titled, New Directions in Osteogenesis Imperfecta Research, the assembled group of basic and clinical care researchers reviewed the current knowledge and looked ahead to potential scientific advances that will improve treatment for people with OI. Presentations and discussion were held on classification systems, effects of drugs on bone function, dental and craniofacial issues in OI, animal and cell models of OI and what they tell us about skeletal and non-skeletal aspects of OI, and concluded with other treatment concerns besides bones.

Many of the speakers took the opportunity to compare and contrast what we know today with information from the first scientific meeting. Fifteen years ago only 4 types of OI were known, recessive inheritance patterns were unheard of and the most frequently used test for OI was a collagen/skin biopsy. Today we refer to 14 different types, recessive forms of OI are suggesting new treatment avenues and the most frequently used test is a DNA analysis. Available drug treatments now include multiple bisphosphonates, and teriparatide (Forteo®) which was studied in adults with OI rather than borrowing data from osteoporosis studies. A potential new drug specifically for OI is being studied. Today we know more about how the drug treatments change bone, and what those changes mean for surgical repair options and daily activity. Knowledge about dental and craniofacial issues is slowly becoming more complete. Recent studies have more clearly identified the extent of tooth and jaw problems beyond dentinogenesis imperfecta. The number of animal models for OI has grown along with the ability to use them to understand how OI affects different body systems, and evaluate potential treatments. Systems are being developed for more closely coordinating animal and human studies to explore important questions more efficiently. The area of non-skeletal issues related to OI has gained more attention over the past years. Decreased lung function is no longer only seen as a by-product of severe rib cage and spine curves, but is known to be an issue for all types of OI. New research is targeting the unanswered questions about cardiac issues and pregnancy for women who have OI. Advances in the technology and surgical repair options that are available to the general population to treat hearing loss have been shown to be effective for most people who have OI.

The formal presentations were followed by an evening program during which small groups gathered to talk about the future. Lists of research ideas for clinical care, surgical care and genetics were prepared by each group. These ideas were discussed at length the following morning and will become the foundation for a research agenda for the next several years.

Participants came away from the meeting with new ideas for collaborating on the next wave of studies.