

**Improving Musculoskeletal Outcomes for Individuals with Osteogenesis Imperfecta:
Workshop Summary
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The Osteogenesis Imperfecta Foundation hosted its 10th Scientific Meeting, “Improving Musculoskeletal Outcomes for Individuals with Osteogenesis Imperfecta (OI)” in Chicago, Illinois on April 7-9, 2010. Seventy-eight people including individuals with OI, their family members, basic researchers, clinicians, therapists and trainees met to initiate a multidisciplinary effort whose long term goal is to 1) summarize the state of knowledge regarding the musculoskeletal aspects of aging with OI; and 2) explore the potential for new diagnostic and therapeutic techniques for the treatment of OI; and 3) develop better quantitative measurement tools with which to analyze the outcome of these interventions.

Workshop sessions focused on a broad array of topics. First, the paucity of studies on aging with OI was discussed and, drawing from the osteoporosis literature, the risks of aging poorly were underscored. Drawing from bedrest studies and space research, the importance of exercise to maintain both muscle function as well as bone health was reviewed, and exciting new therapies to improve muscle function and bone health were highlighted. The potential for non-invasive technologies designed to measure bone quality in individuals with osteoporosis were discussed as they may serve to better inform researchers and clinicians about the status of bone in individuals with OI. The workshop paid particular attention to the broad range of orthopaedic problems found in OI including spondylolysis/spondylolithesis, scoliosis, long bone fractures and joint replacement: issues that affect a person’s ability to function across the life span. A particular highlight of the conference was a “fireside chat” in which clinicians presented challenging medical and surgical cases and were offered thoughtful assistance for tackling their problems. The workshop closed with a discussion of the need to develop a better understanding of the needs of the adult OI population as well as improved tools for assessing quality of life concerns and treatment outcomes.

Outcomes:

Attendees formed collaborations to

- Expand data on spondylolysis/spondylolithesis prevalence and management
- Develop a protocol to establish prevalence of tendon injuries in adults with OI
- Investigate steps needed to create a set of reference data for bone turnover markers for people with OI
- Plan focus group sessions to be held at the National Conference on OI July 2010, to begin assessing needs of the adult OI population. This would be the first step in an effort to develop a tool for evaluating health status in adults with OI.

Attendees further agreed that a long term goal should be to develop a study of the impact of aging in OI. There is a potential for including this study within the OI Foundation’s Linked Clinical Research Center Program. Meeting attendees also recommended short term projects to include a program for maintaining bone health aimed at adults with OI and creating additional opportunities for health care providers to connect and share questions/expertise about care for adults with OI.

Publication Plans:

- Lay summary to be posted on the OI Foundation website and presented at the OI Foundation National Conference July 8-10, 2010
- Full summary to be published in the on-line journal, *Journal of Musculoskeletal and Neuronal Interactions*.