We are pleased to report that the “Initial Report of the Osteogenesis Imperfecta Adult Natural History Initiative” has been published in Orphanet Journal of Rare Diseases! This article reports the results of the survey of adults with OI conducted in 2010-2011.

The project was truly a collaborative endeavor between the OI community, the OI Foundation, and the OI-ANHI research team. Principal investigator, Dr. Laura Tosi, MD, a member of the OI Foundation’s Board of Directors and Medical Advisory Committee, led the research team. Other team members included Melanie Rak, MD and Barbara Simmonds from the OI community, Matthew Oetgen, MD, Marianne Floor, MD, MPH, Annie Kennelly, and Robert McCarter, ScD from Children’s National Health System in Washington, DC, Melissa D. Simpson, DVM, PhD, and Fergus McKiernan, MD from the Marshfield Clinic in Wisconsin, Carole A. Tucker, PT, PhD, PCS, RCEP from Temple University in Philadelphia, and Mary Beth Huber from the OI Foundation.

Over 1,000 individuals responded to the survey...a tribute to the generosity, spirit of mutual support, and high degree of interest in quality of life and health that is characteristic of the OI community. The survey sought to identify previously unrecognized areas of health concern faced by adults with OI. The article is a first step in underscoring that the needs of individuals with OI are often unique. This was a “Patient Reported” survey --adults with OI provided the information without using a doctor or interviewer as a filter. The results describe the questions/concerns that are important to the OI adult community.

Summary of Findings
The article reports that the health concerns of adults with OI go beyond fractures and include a range of specific health issues, treatment options/complication questions, and health care provider knowledge concerns. While general physical health status was lower than the US adult average, people with OI were found to be more similar to the general population than might have been expected in many areas including mental health, diabetes, and cancer. A profile of the people taking the survey found among other things:

- Vitamins and/or dietary supplements were taken by 65%
- Pain medicines were taken by 40%
- Blood pressure medicines were taken by 32%
- One third of responders reported exercising regularly.
- Only 32% of survey takers were confident in their doctor’s knowledge about OI.
- Pain interfered with activities of daily living for people with OI more often than for people in the general US population

Specific health concerns include: musculoskeletal system (tendons, muscle), pulmonary system (shortness of breath, cough, sleep apnea, wheezing/asthma), heart (heart attack, heart valve issues), and gastrointestinal issues. Other concerns included fractures, hearing, fragile teeth, glaucoma and numbness.

These finding suggest that there is a great need to learn more about:

- Effects of age and OI severity on general health and on specific health issues.
- How OI affects treatments, surgery and medical test options.
- Each of the identified health concerns.
- Quality of life across multiple domains (for example, pain interference, social roles, anxiety) in adults with OI

So where do we go from here?
The publication of “Initial Report of the Osteogenesis Imperfecta Adult Natural History Initiative” is just a small step forward in the Foundation’s efforts to better define the health concerns and care needs of the
community. Information from this report has already been put to use. Concerns and suggestions for care based on the report have been included in

- The new Medical Education pages on the OI Foundation website
- The new outline for health care during the adult years that is currently being written
- The Brittle Bone Disorders Consortium’s The OI PROMIS® Pilot Project, which continues the work initiated by the OI-ANHI survey. The goal of this successor project is to validate the PROMIS® instruments for OI so that they can be used in the future to help compare and evaluate the results of alternative treatment options.

**You can help!**
The authors of this report hope that the community of OI adults will continue to contribute to finding answers about how to manage OI after childhood. Clearly it is essential to involve as many members of the adult OI community as possible in the ongoing studies to keep moving this important research forward. If you live near one of the Brittle Bone Disorders sites, please join the Longitudinal Study. The information collected at a series of once a year visits will help clarify many of the questions raised by the OI ANHI study. Every adult with OI is asked to join the OI Contact Registry so you will be included in all of the follow up surveys.

The published report is available free on-line. A link to the paper is on the OI Foundation website or you can find it through the Orphanet Journal at http://www.ojrd.com/content/10/1/146. It is important to recognize that the paper was written for a medical audience and not for the general public. We encourage you to share the article with your primary care doctor.

Finally, the authors are most eager to receive feedback from the OI community about the publication. Let us know what surprised you in the results and what connects with your personal experience. One problem with this study is that men with OI were under represented. Ideas for engaging more men in the next study would be greatly appreciated. Send your thoughts or questions to Mary Beth Huber at mhuber@oif.org.

**SO….THANK YOU!** Without the enthusiastic support of the OI community, this project would have never been possible. In addition, the authors of OI-ANHI wish to thank the OIF for its enthusiastic support of this project, and in particular, the leadership of Ms. Tracy S. Hart, CEO. They also gratefuly acknowledge the contributions of Angela M. Mancuso, Elizabeth J. Simmonds, and Mr. Kyle Mulroy for their roles in initiating this project and recruiting participation from the OI community. They also thank Winslow M. Blankenship and Lauren Greco for their assistance in survey development, Cristine Agresta for her assistance with preliminary data analysis, and Cara Goerlich for her editing support. Beyond all measure, the OI Foundation and the authors of OI-ANHI are grateful and indebted to the adult OI community for their personal generosity and patience without which this project would never have succeeded.

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