

OIF Advocacy in Action

OIF Joins Advocates At First Ever Capitol Hill Briefing on Rare Bone Disease March 2015

The OI Foundation led the effort to organize a Capitol Hill Congressional Briefing on March 18, 2015 with other members of the Rare Bone Disease Advocacy Alliance. The briefing, held at the U.S. Capitol in Washington, DC, was the first ever forum dedicated to educating Members of Congress and legislative staff about the impact of rare bone disorders and the need for greater federal research funding.

OIF's Tracy Smith Hart moderated a prominent panel of speakers that included the Co-Chairs of the Congressional Rare Disease Caucus: Congressman Leonard Lance (R-NJ) and Congressman Joseph Crowley (D-NY). Both Congressmen spoke about the importance of the Alliance's advocacy work and affirmed their commitment to working with their colleagues in Congress to elevate attention of rare bone disorders in the federal budget process.

The audience, which included legislative staff from the House and Senate including committees with jurisdiction over the National Institutes of Health (NIH), heard presentations from Dr. Joan McGowan, Director of the Division of Musculoskeletal Diseases at the NIH's National Institute of Arthritis and Musculoskeletal and Skin Diseases, and from Dr. Jay Shapiro, Director of the Osteogenesis Imperfecta Program at the Kennedy Krieger Institute. Drs. McGowan and Shapiro gave an update on research efforts from the government and academic perspectives and spoke about the need for increased funding and the need to encourage researchers and physicians to enter the rare bone disease field.

Finally, Jack Kelly, President of the Lymphangiomatosis & Gorham's Disease Alliance, and Elspeth Birdsdall, Chair of the OsteoPETrosis Society, with the assistance of her husband Pat, delivered powerful and impassioned speeches about the difficulties of living with a rare bone disorder. Their testimony highlighted the physical and emotional impact that rare bone diseases have had on them and their families and the challenges associated with finding informed health care practitioners.

The briefing was timed to coincide with the beginning of the federal budget process as Members of Congress develop funding levels for the NIH. The OIF will continue its strong federal advocacy as an organization and as a proud founding member of the Rare Bone Disease Advocacy Alliance in the weeks, months and years ahead to increase the federal government's response to the needs of the OI community.