



## Congressional Briefing: “The Future of Rare Bone Disease Research”

Wednesday, March 18, 2015  
11:00 AM - 12:00 PM  
121 Cannon House Office Building  
Washington, DC  
RSVP: [rarebonedisease.eventbrite.com](http://rarebonedisease.eventbrite.com)

The Rare Bone Disease Advocacy Alliance invites you to attend a discussion designed to generate ideas and solutions to move forward the state of science for rare bone diseases. Featuring:

### **Rep. Leonard Lance and Rep. Joseph Crowley**

Co-chairs of the *Congressional Rare Disease Caucus*

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A panel of prominent stakeholders from government, academic research institutions and the advocacy community, including:

- **Joan A. McGowan, PhD**  
Director, Division of Musculoskeletal Diseases at the National Institute of Arthritis and Musculoskeletal and Skin Diseases, National Institutes of Health
- **Jay R. Shapiro, MD**  
Director, Osteogenesis Imperfecta Program, Kennedy Krieger Institute, Johns Hopkins Hospital  
Professor in the Department of Physical Medicine and Rehabilitation at the Johns Hopkins University
- **Jack Kelly**  
Jack Kelly, President, Lymphangiomatosis & Gorham’s Disease Alliance
- **Tracy Smith Hart**  
Chief Executive Officer, Osteogenesis Imperfecta Foundation
- **Elsbeth Birdsdall**  
Chair, The OsteoPETrosis Society

An unknown, but substantial, number of Americans are afflicted by unique disorders of the bone that are painful, debilitating and lead to additional and often life-threatening respiratory, coronary, circulatory, pulmonary and other body system complications.

Please join us for a discussion about ways to improve the quality of life for those affected by rare bone diseases through a strengthening of the federal government’s response to this national public health issue.

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