

RARE BONE DISEASE RESEARCH SUMMIT

FUTURE DIRECTIONS

***Expanding Our Knowledge and Developing Strategies to
Accelerate Research of Rare Bone Diseases***

**Wednesday, September 19, 2012
Turner Auditorium · Baltimore, MD**

Presented by the Rare Bone Disease Patient Network

*Fibrous Dysplasia Foundation · International Fibrodysplasia Ossificans Progressiva Association · Lymphangiomatosis & Gorham's Disease Alliance
(LGD Alliance) · Melorheostosis Association · MHE Research Foundation · Osteogenesis Imperfecta Foundation · Paget Foundation For Paget's
Disease of Bone and Related Disorders · Soft Bones, Inc · XLH Network*



RARE BONE DISEASE PATIENT NETWORK

Meeting Chairs

Dr. Jay Shapiro

Director of the Bone and Osteogenesis Imperfecta Clinic, Kennedy Krieger Institute

Dr. Emily Germain-Lee

Director of Bone Research Program, Kennedy Krieger Institute

The Rare Bone Disease Research Summit Planning Committee is pleased to announce the following confirmed speakers:

Welcoming Remarks:

Joan McGowan, PhD, NIAMS and Steve Groft, PharmD, NIH Office of Rare Diseases

Michael Collins, MD, NIDCR/NIH — Fibrous Dysplasia

Michael Econs, MD, Indiana University — XLH

Emily Germain-Lee, MD, Kennedy Krieger Institute — Albright Hereditary Osteodystrophy

Maurizio Pacifici, PhD, University of Pennsylvania — Multiple Hereditary Exostoses

Jay Shapiro, MD, Kennedy Krieger Institute — Osteogenesis Imperfecta

Eileen Shore, PhD, University of Pennsylvania — Fibrodysplasia Ossificans Progressiva

Michael Whyte, MD, Washington University and Shriners Hospital, St. Louis — Hypophosphatasia

TO REGISTER, please contact Jenny Stup at the Osteogenesis Imperfecta Foundation at jstup@oif.org or 800-981-2663. There is no registration fee, but a fee of \$25 for food costs is required.

For more information, please contact the organizers Tracy Hart, OI Foundation at 301-947-0083 or Charlene Waldman, at 917-797-4946, Sarah Ziegler at 561-315-9149