

RARE BONE DISEASE RESEARCH

FUTURE DIRECTIONS SUMMIT

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

September 19, 2012

Turner Auditorium (Johns Hopkins Hospital Campus) • 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:

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 Exostoses

Jay Shapiro, MD, Kennedy Krieger Institute — Osteogenesis Imperfecta

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

Matthew Warman, MD, Boston Children's Hospital – Gorham's Disease

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.