



**1<sup>st</sup> International Conference on Generalized Lymphatic Anomaly and Gorham-Stout Syndrome**

**June 7-8, 2013**

**Hyatt Regency Hotel, Bethesda, MD**

**Conference purposes:** 1) Bring together leaders in bone and endothelial cell biology to discuss the latest advances in GLA and GSS basic science and clinical research; 2) Develop new avenues of research and foster collaboration among investigators studying these rare diseases of the lymphatic system; and 3) Generate a comprehensive review comprised of the proceedings of the meeting for publication.

**FRIDAY (June 7<sup>th</sup>, 2013) 2:00 pm – 6:00 pm**

**2:00 – 2:05 pm**            ***Introduction***

Nupur Garg (Program Director, LMI)

**SESSION 1: RECENT ADVANCES IN BASIC SCIENCE RESEARCH**

**Discussion Leader:** Bjorn Olsen (Harvard School of Dental Medicine, USA)

**2:05 – 2:30 pm**            ***Regulation of developmental and pathological lymphangiogenesis***

Marc Achen (Peter MacCallum Cancer Centre, Melbourne, Australia)

**2:30 – 2:55 pm**            ***The function of the VEGF family in bone biology***

Bjorn Olsen (Harvard School of Dental Medicine, USA)

**2:55 – 3:20 pm:**            ***Regulation of osteoclast activity by the VEGF-C/VEGFR3 axis***

Lianping Xing (University of Rochester Medical Center, USA)

**3:20 – 3:45 pm**            ***Molecular regulation of osteoclast activity as a basis for therapeutic strategies***

Roland Baron (Harvard School of Dental Medicine, USA)

**3:45 – 4:10 pm**            ***Refreshment break***

**SESSION 2: PRECLINICAL MODELS TO STUDY LYMPHANGIOMATOSIS/GORHAM'S DISEASE**

**Discussion Leader:** Mike Dellinger (University of Texas Southwestern Medical Center, USA)

**4:10 – 4:35 pm**            ***In vitro models to study GLA and GSS***

Ramani Ramchandran (Medical College of Wisconsin, USA)

**4:35 – 5:00 pm**            ***Zebrafish as a model to study osteogenesis and lymphangiogenesis***

Stefan Schulte-Merker (Hubrecht Institute, Royal Netherlands Academy of Arts and Sciences, Netherlands)

**5:00 – 5:25 pm**            ***Animal model of pulmonary lymphangiomatosis***

Donald McDonald (University of California San Francisco, USA)

**5:25 – 5:50 pm**            ***Mechanisms of VEGFR2-induced developmental and pathological lymphangiogenesis***

Mike Dellinger (University of Texas Southwestern Medical Center, USA)

**6:00 – 8:00 pm**            ***Reception***

**SATURDAY (June 8<sup>th</sup>, 2013) 8:25 am – 4:15 pm**

**8:25 – 8:30 am**            ***Introduction***

Jack Kelly (President, LGDA)

**SESSION 1: CLINICAL FEATURES OF GLA AND GSS**

**Discussion Leader:** Harry Kozakewich (Boston Children's Hospital and Harvard Medical School, USA)

**8:30 – 8:55 am**            ***History of GLA and GSS***

Marlys Witte (University of Arizona, USA)

**8:55 – 9:20 am**            ***Terminology and Classification System of Lymphatic Anomalies***

Gulraiz Chaudry (Boston Children's Hospital and Harvard Medical School, USA)

**9:20 – 9:45 am**            ***Histopathology of GLA and GSS***

Paula North (Medical College of Wisconsin, USA)

**9:45 – 10:10 am**            ***Clinical Features of GLA and GSS***

Cameron Trenor (Boston Children's Hospital and Harvard Medical School, USA)

**10:10 – 10:35 am**            ***Refreshment break***

**SESSION 2: TREATMENTS FOR GLA AND GSS**

**Discussion Leaders:** Joel Moss (NHLBI/NIH) and Michael Collins (NIDCR/NIH)

**10:30 – 10:55 am**            ***Treatments for GLA and GSS***

Juan Carlos Lopez Gutierrez (La Paz Children's Hospital, Spain)

**10:55 – 11:20 am**            ***Update on Rapamycin clinical trial***

Denise Adams (Cincinnati Children's Hospital Medical Center, USA)

**11:20 – 11:45 pm**      ***Biomarkers and treatments for GLA and GSS***

Erik Eklund (Lund University, Sweden)

**11:45 – 12:10 pm**      ***Advances in lymphatic imaging: Preclinical and clinical studies***

Eva Sevick-Muraca (University of Texas, Houston Health Science Center, USA)

**12:10 – 2:00 pm**      ***Lunch and breakout sessions***

**2:00 – 2:20 pm**      ***Reports of breakout sessions***

**SESSION 3: GENETIC CAUSES OF BONE AS WELL AS VASCULAR AND LYMPHATIC ANOMALIES**

**Discussion Leader:** Matt Warman (Boston Children's Hospital and Harvard Medical School, USA)

**2:20 – 2:45 pm**      ***Genetic causes of inherited and sporadic vascular and lymphatic anomalies***

Nisha Limaye (de Duve Institute, Université Catholique de Louvain, Belgium)

**2:45 – 3:10 pm**      ***Genetic causes of overgrowth syndromes and their potential relationship to GLA and GSS***

Matt Warman (Boston Children's Hospital and Harvard Medical School, USA)

**3:10 – 3:35 pm**      ***Genetic imbalances in GLA and GSS***

Juan Carlos Lopez Gutierrez

**3:35 – 4:00 pm**      ***A Molecular Genetic Approach to the Pathogenesis of Generalized Lymphatic Anomaly and Gorham-Stout Syndrome***

Michael Levine (Children's Hospital of Philadelphia, USA)

**4:00 – 4:15 pm**      ***Concluding remarks***

Mike Dellinger and Bjorn Olsen

**Attendees**

Alison Boyce (Children's National Medical Center, Washington, DC)

Francine Blei (St. Luke's - Roosevelt Beth Israel)

Belinda Dickie (Cincinnati Children's Hospital)

Peter Dickie (Cincinnati Children's Hospital)

Nicola Fabbri (Memorial Sloan Kettering Cancer Center)

Tiffany Ferry (LMI)

Sandy Goldfarb (LGDA)

Scott Goldfarb (LGDA)

Mrinal Gounder (Memorial Sloan Kettering Cancer Center)

Steve Groft (Office of Rare Diseases, NCATS/NIH)

Silvio Gutkind (NIDCR/NIH)

Mike Kelly (Medical College of Wisconsin)

Giannoula Lakka-Klement (Tufts University)

Lisa Klepper (LGDA)

Frank McCormack (University of Cincinnati)

Joan McGowan (NIAMS/NIH)

Alfredo Molinolo (NIDCR/NIH)

John Reith (University of Florida)

Stan Rockson (Stanford University Medical Center)

Jochen Roessler (Universitäts Klinikum Freiburg, Germany)

Laura Tosi (Children's National Medical Center)

Hung Tsen (NIAMS/NIH)

Charlene Waldman

Jason Wan (NIDCR/NIH)

Brant Weinstein (NICHD/NIH)

Li-Chin Yao (University of California/San Francisco)

David Zawieja (Texas A & M Health Science Center)