

LGDA/LMI International Scientific Conference on Complex Lymphatic Anomalies

September 29 – 30, 2023

Updated: July 18, 2023

September 29

4:00 – 4:10 pm

Introduction

Michael Kelly, MD, PhD, Executive Director, LGDA

4:10 – 4:20 pm

Patient Voice

David Williams, Executive Director and Board Chair, LGD Alliance Europe

BASIC SCIENCE SESSION: GENETIC CAUSES OF COMPLEX LYMPHATIC ANOMALIES

Moderator: Sarah Sheppard, MD, PhD, MSTR, Clinical Investigator

Eunice Kennedy Shriver National Institute of Child Health and Human Development, Maryland USA

4:20 – 4:40 pm

Genetic of CLAs

Miikka Vikkula, MD, PhD, Professor of Human Genetics and Co-Director
de Duve Institute, Université catholique de Louvain, Brussels, Belgium

4:40 – 5:00 pm

Expanded Genetic Causes in CLAs using Ultra-Deep Sequencing and Unconventional Samples

Dong Li, PhD, Assistant Professor of Pediatrics

University of Pennsylvania, Center for Applied Genomics and Children's Hospital of Philadelphia, Pennsylvania, USA

5:00 – 5:20 pm

Detection of PIK3CA Mutations in Aspirated Cyst Fluid is Comparable to Surgically Resected Tissues: Minimally Invasive Diagnostics for Lymphatic Malformations

James Bennett, MD, PhD, Associate Professor

Department of Pediatrics, Division Genetic Medicine, University of Washington, Vascular Anomalies Program, Seattle Children's Hospital and Center for Development Biology and Regenerative Medicine, Seattle Children's Research Institute, Washington, USA

5:20 – 5:40 pm

Targeting Proteostasis Defects Downstream of PI3K/mTOR Hyperactivation in Lymphatic Anomalies

Carrie Shawber, PhD, Associate Professor of Reproductive Sciences

Departments of OBGYN and Surgery, Columbia University Irving Medical Center, New York, USA

5:40 – 6:00 pm

Matching Genetic Variant with Appropriate Medical Therapy – Proposed VATCH Clinical Trial

Alex Borst, MD, Assistant Professor of Pediatrics

Penn Medicine and the Hemostasis and Thrombosis Center at Children's Hospital of Philadelphia, Pennsylvania, USA)

September 30

8:00 – 8:05 am

Introduction

Michael Dellinger, PhD, Scientific Director
Lymphatic Malformations Institute, Texas, USA

8:05 – 8:15 am

Patient Voice

David Williams, Executive Director and Board Chair, LGD Alliance Europe, Netherlands

CLINICAL SESSION: PATIENT CENTERED RESEARCH AND REGISTRIES

Moderator: Matthew Hawkins, MD, Associate Professor and Medical Director
Emory University School of Medicine, Department of Radiology and Imaging Sciences, and Vascular Anomalies
Clinic at Children's Healthcare of Atlanta, Georgia, USA

8:15 – 8:35 am

*Visualizing the Lymphatic Vessels and Flow with High-Resolution Ultrasound and Microvascular Flow Imaging**

Willemijn M. Klein, MD, PhD
Department of Medical Imaging Radiology, Radboud University Medical Center Nijmegen, NL

8:35 – 8:55 am

KLA: Update from the BCH Registry

Whitney Eng (Seattle Children's Hospital, USA)

8:55 – 9:15 am

Complex Lymphatic Anomalies: Report on a Patient Registry Using the Latest Diagnostic Guidelines

Jochen Rössler, MD, PhD
University Hospital Bern, Pediatric Hematology and Oncology, Switzerland

9:15 – 9:35 am Break

9:35 – 9:45 am

Patient Voice

David Williams, Executive Director and Board Chair, LGD Alliance Europe

BASIC SCIENCE SESSION: PRECLINICAL MODELS OF CLAs

Moderator: Elisa Boscolo, PhD, Associate Professor
Division of Experimental Hematology and Cancer Biology, Cancer and Blood Disease Institute Cincinnati
Children's Hospital Medical Center, Ohio, USA

9:45 – 10:05 am

Zebrafish Models of CCLA Due to Ras GTPases

Sarah Sheppard, MD, PhD, MSTR, Clinical Investigator
Eunice Kennedy Shriver National Institute of Child Health and Human Development, Maryland USA

10:05 – 10:25 am

Role of NRAS Q61R in the Pathogenesis of Kaposiform Lymphangiomatosis

Tim D. Le Cras, PhD

Professor of Pediatrics, Associate Dean for Graduate Education
University of Cincinnati and Cincinnati Children's Hospital

10:25 – 10:45 am

Cellular Mechanisms Underlying PIK3CA-driven Lymphatic Anomalies

Hans Schoofs, PhD Student

Uppsala University, Department of Immunology, Genetics, and Pathology, Sweden

10:45 – 11:05 pm

The Role of Hyperactive KRAS Signaling in Complex Lymphatic Anomalies

Mike Dellinger, PhD, Associate Professor

UT Southwestern Medical Center, Texas, USA

11:05 - 12:05 pm Lunch

2022 Young Investigator Awardees

Analysis of a New Therapeutic Approach to Inhibit Osteolysis in Gorham-Stout Disease

Michela Rossi, PhD

Bone Physiopathology Research Unit, Translational Pediatrics and Clinical Genetics Research Division, Bambino
Gesù Children's Hospital, IRCCS, Rome, Italy

Mentor: Andre Del Fattore

Molecular Mechanisms of EPHB4 Pathogenesis – Towards New Treatment Development for Lymphatic Anomalies

Silvia Martin Almedina, PhD

Molecular and Clinical Sciences Institute, St George's University of London, UK

Mentor: Pia Ostergaard

12:05 – 12:15 pm

Patient Voice

David Williams, Executive Director and Board Chair, LGD Alliance Europe

CLINICAL SESSION: CLINICAL ADVANCES

Moderator: Denise Adams, MD, Director

Comprehensive Vascular Anomalies Program at Children's Hospital of Philadelphia, Pennsylvania, USA

12:15 – 12:35 pm

Treatment of CLAs – overview

Kiersten Ricci (Cincinnati Children's Hospital Medical Center, USA)

12:35 – 12:55 pm

Lymphatic Effusions in Infancy

Ionela Iacobas, MD, Associate Professor

Medical Director, TCH Vascular Anomalies Center, Texas Children's Hospital and Baylor College of Medicine,
Texas, USA

12:55 – 1:15 pm

Spectrum of Gorham-Stout Disease Exploring a Single Center Pediatric Case Series

Sabrina Buonuomo, MD and Ippolita Rana, MD

Rare Disease and Medical Genetics, Bambino Gesù Children's Hospital, IRCCS Rome, Italy

1:15 – 1:35 pm

Experience in the Use of Alpelisib in Patients with Vascular Anomalies

Paloma Triana, MD

Pediatric Surgery, Children's Hospital Universitario La Paz, Spain

1:35 – 1:55 pm Break

BASIC SCIENCE SESSION: NEW TECHNOLOGIES FOR CLA RESEARCH

Moderator: James Bennett, MD, PhD, Associate Professor

Department of Pediatrics, Division Genetic Medicine, University of Washington, Vascular Anomalies Program, Seattle Children's Hospital and Center for Development Biology and Regenerative Medicine, Seattle Children's Research Institute, Washington, USA

1:55 – 2:15 pm

HAM, A Novel Pleurodesis Agent Inspired by PAM for LAM

Frank McCormack, MD, Professor and Director

Plumony, Critical Care, and Sleep Medicine, University of Cincinnati, Ohio, USA

2:15 – 2:35 pm

Engineering Approaches for Understanding Cellular Dynamics in GLA

William Polacheck, Assistant Professor of Biomedical Engineering

University of North Carolina at Chapel Hill, North Carolina, USA

2:35 – 2:55 pm

Leveraging Tissue Engineered Lymphatic Malformation Models and Patient Genomics to Study Response to Medical Therapy

Brandon Dixon, Professor

Parker H. Petit Institute for Bioengineering and Bioscience, Georgia Institute of Technology, Georgia, USA

CLINICAL SESSION: ADVANCES IN IMAGING OF CLAS

Moderator: Yoav Dori, MD, PhD

Director of the Jill and Mark Fishman Center for Lymphatic Disorders and Lymphatic Research, Children's Hospital of Philadelphia, Pennsylvania, USA

2:55 – 3:15 pm

Integrative Diagnostic Imaging of Tissue Biopsies for Spatial Deep-phenotyping of Lymphatic Anomalies

René Haegerling, Clinical Geneticist and Research Group Leader

Charité – Universitätsmedizin Berlin and Berlin Institute of Health Center for Regenerative Therapies, Berlin, Germany

3:15 – 3:45 pm

Interventions in Complex Lymphatic Anomalies: Current and Future Directions

Deb Rabinowitz, MD, Director

Interventional Radiology, Division Chief and Nemours Lymphatics Disease Program, Director
Nemours Children's Hospital-Delaware, Delaware, USA

3:45 – 4:05 pm

*Communication, Health Care Delivery, and Burdens of Disease in Complex Lymphatic Anomalies**

Bryan Sisk, MD

Assistant Professor, Pediatric Hematology and Oncology Director of Research, Bioethics Research Center, Co-Director, Vascular Anomalies Center, Washington University School of Medicine

4:05 – 4:15 pm

Concluding remarks

Mike Kelly, MD, PhD and Mike Dellinger, PhD

*Drs. Bryan Sisk and Willemijn Klein presentations switched from previous agenda.