LBSL Patient & Family Conference

JULY 24-26, 2026

Speaker Bios

Josh Beck

Mr. Beck was diagnosed with LBSL as a child and has lived with LBSL for more than 20 years. He works in his county's assessor's office, and in his free time, he enjoys LARPing, or live action role playing. (It is fantastic exercise for his legs!) He lives in West Virginia.

Michelle Campbell, PhD

Associate Director, Stakeholder Engagement and Clinical Outcomes, U.S. Food and Drug Administration, Office of Neuroscience

Dr. Campbell is the Associate Director for Stakeholder Engagement and Clinical Outcomes in the Office of Neuroscience, Office of New Drugs (OND) in FDA's Center for Drug Evaluation and Research. Her focus is in patient-focused drug development and the use of patient experience data in the regulatory setting.

Shannon Connelly, MS

Shannon is an incoming PhD student in Human Genetics at the University of Miami. They hold a master's degree in Bioinformatics from Georgetown University. Their research focuses on genotype-phenotype associations in LBSL. While a student at Georgetown, Shannon interned with the Moser Center for Leukodystrophies studying phenotype-genotype associations in LBSL.

Ali Fatemi, MD, MBA

Chief Medical Officer; Director, Moser Center for Leukodystrophies at Kennedy Krieger Institute

Dr. Fatemi is the Chief Medical Officer at Kennedy Krieger Institute, a pediatric neurologist and the director of the Division of Neurogenetics and the Moser Center for Leukodystrophies, and an investigator at the Hugo W. Moser Research Institute at Kennedy Krieger Institute.

In addition to overseeing the medical faculty at Kennedy Krieger, Dr. Fatemi evaluates children with a variety of neurologic problems at the Outpatient Center and in Leukodystrophy Clinic. His greatest interest is in genetic conditions that affect the brain's white matter and in genetic causes of neurodevelopmental disabilities. To this end, he dedicates much of his time to research into these conditions, and contributes his expertise to patient advocacy groups, medical and research organizations and meetings, and clinical trials.

Jessica Fernandez, MD

Department of Physical Medicine and Rehabilitation, Kennedy Krieger Institute

Dr. Fernandez participates in general rehabilitation clinics as well as multiple specialty clinics at Kennedy Krieger. She cares for many patient populations including individuals with cerebral palsy, spina bifida, leukodystrophy, osteogenesis imperfecta, Angelman syndrome and skeletal dysplasia. She has a special interest in health care policy, transition of care and advocating for people with disabilities.

Amena Smith Fine, MD, PhD

Assistant Professor of Neurology and Developmental Medicine, Kennedy Krieger Institute

Dr. Fine has a neurogenetics clinic and works in the multidisciplinary leukodystrophy clinic at the Moser Center for Leukodystrophies. In addition, Dr. Fine has a clinic in the Center for Development and Learning. The focus of Dr. Fine's primary research is to determine the neural substrates of clinical impairment in LBSL and validate the longitudinal use of wearable technology to identify clinically meaningful quantitative performance measures.

Stephanie Gilliam

Ms. Gilliam is, above all, a devoted wife and mother to two boys living with LBSL. Born and raised in St. Louis, Missouri, she has worked in the finance industry for the past 15 years. She is dedicated to providing her boys with the best possible life while connecting and collaborating with other families affected by this rare disease.

Jennifer Keller, MS, PT

Research Physical Therapist, Kennedy Krieger Institute

Ms. Keller has conducted research under the guidance of the Center for Movement Studies for over 15 years. Her publications and interests focus on the application of movement control research to rehabilitation for people with neurological disorders.

Janine Lewis, MS

Director of Research Operations, National Organization for Rare Disorders

Ms. Lewis leads research operations for the National Organization for Rare Disorders (NORD), utilizing 20+ years of experience in patient advocacy, genetic counseling, and health information, including 15 years directing the NIH-funded GARD center. Specializing in complex genomic communication for families, she now focuses on providing, tools and infrastructure to accelerate diagnosis and treatment.

Eric Mallack, MD, MBE, MS

Director of Clinical Research, Moser Center for Leukodystrophies at Kennedy Krieger Institute

Dr. Mallack oversees the clinical, neuroimaging and clinical trial research in the Moser Center and Clinical Trials Unit at the Institute. Clinically, he sees patients in the Newborn Screening Follow-up Clinic, Multidisciplinary Leukodystrophy Clinic and Neurogenetics Clinic. In addition to providing clinical care for patients of all ages across all leukodystrophies, he serves (or has served) as an investigator for multiple international clinical trials in gene and novel small molecule therapy for neurodegenerative diseases.

Beth McGinn

Co-founder, Cure LBSL

Together with her husband, Mike, Beth co-founded Cure LBSL in 2013 after their 3-year-old daughter was diagnosed with LBSL. Ms. McGinn served as the executive director of Cure LBSL from its inception until February 2025, and she is also the vice president of communications for a trade association in Washington, D.C. A relentless advocate, she has two decades of experience in politics and policy across local state and federal levels.

Mike McGinn

Co-founder, Cure LBSL, and CEO, Deos Therapeutics

As CEO of Deos Therapeutics, a patient-funded biotech, Mr. McGinn combines years of consulting experience and his experience as a rare disease dad and co-founder of Cure LBSL to drive innovation and bring potential therapies for LBSL to reality.

Christina Nemeth Mertz, PhD

Assistant Professor of Neurology at the Moser Center for Leukodystrophies, Kennedy Krieger Institute

At Kennedy Krieger, Dr. Nemeth Mertz leads experiments using cell and mouse models to better understand disease mechanisms, find targets for therapy, and determine therapeutic strategy.

Amy Raymond, PhD

Executive Director, Therapeutic Strategy Lead, Rare Disease & Cellular and Genetic Medicines at Worldwide Clinical Trials

Dr. Raymond is the Executive Director and Therapeutic Strategy Lead for Rare Disease at Worldwide Clinical Trials. A molecular biologist by training with a PhD from San Diego State University, she brings more than two decades of drug discovery and clinical operations experience to the rare disease landscape. Dr. Raymond specializes in navigating complex clinical trials for cutting-edge cellular and genetic medicines. She is highly regarded across the rare disease community for her focus on meaningful patient engagement, optimized trial design, and accelerating therapeutic pipelines to deliver critical answers to families worldwide.

Lisa Schäfer, MD

Department of Neurology, Leukodystrophy Outpatient Clinic, Leipzig University Medical Center

Dr. Schafer is a psychologist and researcher specializing in behavioral medicine and neuropsychology in rare white matter disorders. After completing psychology studies at the University of Bremen, she worked as a research assistant in the Behavioral Medicine research unit at Leipzig University. In 2021, she earned a PhD from the Faculty of Psychology at Leipzig University. Since 2018, she has been working at the Leukodystrophy Outpatient Clinic at Leipzig University Hospital under the direction of Dr. Wolfgang Köhler and Dr. Caroline Bergner. In this role, she conducts cognitive testing during follow-up examinations and serves as the primary contact for patients regarding psychological issues.

Brad Schlaggar, MD, PhD

President and CEO, Kennedy Krieger Institute

In addition to serving as President and CEO of Kennedy Krieger, Dr. Schlaggar is a child neurologist and developmental cognitive neuroscientist, and professor of neurology and pediatrics at The Johns Hopkins University School of Medicine. At the Institute, Dr. Schlaggar leads a team of more than 2,700 full and part-time staff and faculty members to advance the organization's long-standing mission of improving the lives of children, adolescents and young adults with disorders and injuries of the brain, spinal cord and musculoskeletal system.

Rasangi Tennakoon

Graduate Student, Cui Lab, University of Toronto

Ms. Tennakoon is a PhD candidate in Biological Chemistry at the University of Toronto studying the molecular mechanisms of Leukoencephalopathy with Brainstem and Spinal Cord Involvement and Lactate Elevation (LBSL) in Dr. Haissi Cui's laboratory. Her research focuses on understanding how disease-causing variants in the DARS2 gene alter RNA splicing and exploring RNA-based therapeutic approaches for LBSL.

Morgan Voigt

Executive Director, Cure LBSL

Ms. Voigt is a Marine wife whose daughter, Madison, was diagnosed with LBSL at age 2. She is also a graduate of Hillsdale College and spent 13 years as news editor. As such, she strives to shine a spotlight on the incredible work that researchers are doing to cure this rare disease. She walks by faith but runs on coffee.

Philip Yeske, PhD

Science & Alliance Officer, United Mitochondrial Disease Foundation

At the UMDF, Dr. Yeske directs scientific strategies to advance diagnoses, treatments, and cures for mitochondrial disorders. An organic chemist by training with a doctorate from Emory University, Dr. Yeske spent over two decades in the pharmaceutical and biotechnology sectors. He previously served as President and CEO of Fluorous Technologies and co-founded the drug discovery firm MS2 Array. Dr. Yeske has been deeply involved in the rare disease space since 2004, combining his professional industry acumen with his personal experience as a rare disease parent. He is widely recognized across the advocacy landscape for his unique ability to unify stakeholder alliances and accelerate therapeutic pipelines for families worldwide.