

2020 LBSL Virtual Conference: "Connection, Collaboration, Cures"

Kennedy Krieger Institute
801 N. Broadway
Baltimore, Maryland, USA
www.KennedyKrieger.org/Leukodystrophy

Saturday, November 14, 2020

(all times indicated are Eastern Time Zone; UTC-5)

- 1:00 - 1:30 p.m. **Welcome & Introductions**
Michael McGinn & Beth Frigola McGinn, *Co-Founders of "A Cure for Ellie"*
S. Ali Fatemi, MD, MBA, *Director, Moser Center for Leukodystrophies*
- 1:30 – 2:30 p.m. **LBSL Natural History Study: An Update of 2 Years of Tracking Patient Changes Using Virtual Assessments**
Amena Smith Fine, MD, PhD, *Assistant Professor, Department of Neurology and Developmental Medicine, Moser Center for Leukodystrophies*
- 2:30 – 3:00 p.m. **Break**
- 3:00 – 4:00 p.m. **Understanding Mitochondria and Mitochondrial Disease: Putting DARS2 in Perspective**
Hilary Vernon, MD, PhD, *Director of the Metabolism Clinic and Barth Syndrome Clinic at Kennedy Krieger Institute*
- 4:00 – 5:00 p.m. **Parent Virtual Social Hour (unrecorded)**

Sunday, November 15, 2020

- 1:00 - 2:30 p.m. **Physical Therapy and LBSL: Management and Treatment Strategies**
Jennifer Keller, MS, PT, *Center for Movement Studies, Kennedy Krieger Institute*
- 2:30 – 3:00 p.m. **Break**
- 3:00 – 3:45 p.m. **How to Talk to Your Child & Loved Ones About a Diagnosis**
Julie Cohen, ScM, *Genetic Counselor, Kennedy Krieger Institute*
- 3:45 – 4:30 p.m. **Closing/Question & Answer Session**



Moser Center for Leukodystrophies
at Kennedy Krieger Institute

Monday, November 16, 2020

- 1:00 - 1:15 p.m. **Overview of Lab Research Advances in Leukodystrophies**
S. Ali Fatemi, MD, MBA
- 1:15 – 2:00 p.m. **Protein Biology of LBSL: Understanding Protein Folding and Function, with Special Emphasis on Proteins and Disease**
Stephen Fried, PhD, *Assistant Professor, Department of Chemistry
Johns Hopkins University*
- 2:00 – 3:00 p.m. **Lab Research Update: An Overview of Recent Progress, Current Work and Future Goals**
Christina Nemeth Mertz, PhD, *Research Associate
Moser Center for Leukodystrophies*
- 3:00 – 3:30 p.m. **Break**
- 3:30 – 4:00 p.m. **Gene Therapy for Leukodystrophies: A Look at Where the Science Stands**
Florian Eichler, MD, *Director, Center for Rare Neurological Diseases,
Massachusetts General Hospital*
- 4:00 – 5:00 p.m. **Questions, Closing Remarks, and Acknowledgements**

