

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

Kennedy Krieger Institute  
801 N. Broadway  
Baltimore, Maryland, USA  
[www.KennedyKrieger.org/Leukodystrophy](http://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**  
Rebecca McClellan, MGC, CGC, *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**

