April 18, 2018

9:00–10:00 Parent/Patient Social
Conference attendees will have the opportunity to meet one another. Beth McGinn will lead introductions. Breakfast will be served. Come for the whole time, or feel free to just stop by!

10:00–10:10 Opening Remarks
Beth and Mike McGinn, founders of A Cure for Ellie

10:10–11:10 Clinical Discussion of LBSL and Clinical Trial
Ali Fatemi, MD, MBA, director of the Moser Center for Leukodystrophies, and associate professor of neurology and pediatrics at Kennedy Krieger Institute and The Johns Hopkins University

11:10–11:20 Break*

11:20–12:20 Management of Mitochondrial Disease: The Role of Supplements and Emergency Protocols
Hilary Vernon, MD, PhD, director of the Metabolism Clinic and Barth Syndrome Clinic at Kennedy Krieger Institute, and assistant professor of pediatrics at The Johns Hopkins University’s Institute of Genetic Medicine

12:20–1:30 Lunch and Parent/Patient Meet-Up
A discussion will be led by an LBSL patient. Attendees are welcome to share what they have learned about LBSL, and to offer patient and parent strategies for living the best life possible.

1:30–2:00 Overcoming Social Challenges Associated with Leukodystrophy and Chronic Illness
Kiley Morgart, LCSW-C, clinical social worker for Kennedy Krieger Institute’s Moser Center for Leukodystrophies
April 18, 2018 continued

2:00–2:30 Advocating for Yourself/Advocating for your Child
Maureen Van Stone, Esq., MS, associate director of the Maryland Center for Developmental Disabilities at Kennedy Krieger Institute and founding director of Project HEAL (Health, Education, Advocacy and Law)

2:30–3:00 Genetics 101: What Does It Mean to Have an LBSL-Specific Mutation?
Rebecca McClellan, genetics counselor at Kennedy Krieger Institute’s Metabolism Clinic

3:00–3:30 One Man’s Perspective on LBSL
Ed Blakey will speak to us about his personal LBSL experience as an adult. You will hear how his journey has unfolded, and will have the opportunity to ask him questions.

3:30–3:40 Break*

3:40–4:10 Fundraising to Find a Cure
Leslie Marsiglia, director of individual giving for Kennedy Krieger Institute

4:10–4:40 Nutrition and LBSL
Elizabeth Enagonio, MS, RD, CSP, LDN, clinical nutritionist for Kennedy Krieger Institute’s Moser Center for Leukodystrophies

4:40–5:15 Meet the Experts*

*Meet the Experts—We will offer “Meet the Experts” sessions during lunches and breaks to allow participants to personally meet and talk with the speakers.
April 19, 2018

9:00–10:00 **Parent/Patient Social**
A discussion will be led by one of our parents. Attendees are welcome to share what they have learned about living with LBSL, and to offer patient and parent strategies for living the best life possible. Come for the whole time, or feel free to just stop by!

10:00–10:45 **Function and Malfunction of Mitochondria and tRNA Synthetases Made Easy**
Prof. Dr. Aleksandra Trifunovic, principal investigator for the Institute for Genetics, CECAD Excellent in Aging Research, University of Cologne

11:00–12:15 **Exercise and Demonstration**
Brittany Hornby, PT, DPT, PCS, physical therapist and Christopher Joseph PT, DPT, director of physical therapy at Kennedy Krieger Institute

12:00-12:15 **Tour of the physical therapy gym on the 3rd floor**
12:15–1:30 **Lunch***

1:30–2:30 **Clinical Studies Update**
Amena Smith, MD, PhD, research fellow at Kennedy Krieger Institute’s Moser Center for Leukodystrophies

2:30–3:30 **Research Update**
Christina Nemeth Mertz, PhD, research fellow at Kennedy Krieger Institute’s Moser Center for Leukodystrophies

3:30–4:00 **Closing Remarks**

*Meet the Experts—We will offer “Meet the Experts” sessions during lunches and breaks to allow participants to personally meet and talk with the speakers.*