Friday, July 31st

8 a.m. – Welcome & Conference Details  
Gretchen Noah & Kate Duren, SLO/RSH Foundation

8:15 a.m. – SMITH-LEMLI-OPITZ Syndrome - Understanding the Syndrome Basics - Dr. Anne Tsai

9:00 a.m. – BEYOND CHOLESTEROL - Antioxidant Treatment for Patients with SLOS - Dr. Ellen Elias

9:45 a.m. – "What it is like having Smith-Lemli-Opitz Syndrome" - Markie Noah, age 11

10:00 a.m. – BREAK

10:20 a.m. – SLOS Challenging Behaviors & Medications - Dr. Elaine Tierney

11:20 a.m. – LUNCH - DISCUSSION: UPDATE ON STAIR and STAIR SLOS Research - Dr. William Rizzo

NOON – Travel to Oregon Health & Science University

1:00 p.m. – STAIR 7001 Research Study: Testing and New/Revised Study Protocol – 
Dr. Anne Tsai, Dr. Kurt Freeman, Dr. Chung Lee and Dr. Jean-Baptiste Roullet
See handout regarding the STAIR 7001 Research Study
1:25 p.m. – Consent Process, Signing Up for the STAIR 7001 Study, Participant Travel Funding – Kara Helgren, Research Study Coordinator at OHSU, Dr. Kurt Freeman and Dr. Jean-Baptiste Roullet

1:40 p.m. – Travel & Visit Schedule, Blood Draws & Collection Schedules - Kara Helgren & Brian Booty

2:00 p.m. – SLOS Appetite, Growth, Growth Chart & Feeding Clinics – Panel of Feeding Experts OHSU Feeding and Swallowing Disorders Clinic: Dr. Kevin Senn, Pediatrician; Nancy Sinden, MS, C.C.C.-S.L.P., and H. Christine Brown, O.T.R./L

2:30 p.m. – Smith-Lemli-Opitz Cookbook and General SLOS Nutrition – Julia Jordan, M.S., R.D., L.D, Manager of OHSU/OCTRI Bionutrition Unit and Dr. Yasemen Eroglu

3:00 p.m. – Autism & Neurocognitive Testing – Dr. Kurt Freeman, Dr. Mina Nguyen- Driver, Dr. Caroline Grantz, Dr. Kersti Pettit-Kekkel

3:30 p.m. – UPDATE ON SLOS RESEARCH - Dr. Robert Steiner

4:00 p.m. – STAIR Research Study Q&A; Study Sign-Up - Dr. William Rizzo, Dr. Jean-Baptiste Roullet,

4:30 p.m. – Travel back to hotel/BREAK

5:30 p.m. – DINNER (5:45 p.m: DINNER DISCUSSION - Pass Out & Discuss Study Questionnaires: Nutrition, Quality of Life, and Pain - Dr. Jean-Baptiste Roullet, and Dr. Semone Myrie *)

Saturday, August 1st

8:00 – CONTINENTAL BREAKFAST & VISITING

8:15 a.m. – FOUNDATION UPDATE - Smith-Lemli-Opitz/RSH Foundation Board of Directors

8:45 a.m. – THRIVING IN HOLLAND - Kate Duren & Dr. Andy Jones (Geneva 17, Jukie - SLO 14, Truman 9)

9:45 a.m. – Services Available for Families

10:00 a.m. – SLOS Autism - Sensory Sensitivity, Accessing Services From Schools - Dr. Audrey Thurm

10:50 a.m. – BREAK

11:00 a.m. – SLOS SLEEP & CHALLENGING BEHAVIOR - Dr. Kurt Freeman

11:45 a.m. – Smith-Lemli-Opitz Syndrome – PANEL OF EXPERTS – Dr. William Rizzo, Dr. Kurt Freeman, Dr. Robert Steiner, Dr. Ellen Elias, Dr. Anne Tsai, Dr. Elaine Tierney, Dr. Yasemen Eroglu, Dr. Jean-Baptiste Roullet

12:30 p.m. – LUNCH

1:45 p.m. – CONFERENCE CLOSING REMARKS - Foundation Board Members: Gretchen Noah & Kate Duren

2:00 p.m. – FAMILY FUN / ACTIVITIES / TOURING

6:00 p.m. – DINNER by the POOL - Sponsored by the SLO Foundation
Speakers Bios:

**Kate Duren:** Kate Duren is an essayist, blogger, and Bringing Baby Home Certified Gottman Educator for couples. The Director of Media Relations for the Smith-Lemli-Opitz Foundation, Kate works to support parents, coordinate communication and collaboration among parents of children with Smith-Lemli-Opitz syndrome. She authors the blog Thriving in Holland (at kateduren.blogspot.com). Find Kate online at twitter.com/kateduren.

**Dr. Ellen Elias:** Dr. Elias is a medical genetics doctor in Aurora, CO and is the director of the Childrens Hospital Colorado Special Care Clinic. Dr. Elias' research involves clinical management of children with Smith-Lemli-Opitz Syndrome.

**Dr. Yasemen Eroglu:** Dr. Eroglu's expertise is in digestive health, medicine, pediatrics, and hepatology (liver disease) with a special focus on hepatology and pediatric gastroenterology. Her clinical and research interests are pediatric liver diseases, general gastroenterology, inflammatory bowel diseases, chronic diarrhea, and malabsorption.

**Dr. Kurt Freeman:** Dr. Freeman sees patients at the Child Development & Rehabilitation Center (CDRC), and is the program director of the IDD Behavioral Pediatrics Treatment Program. The program focuses on toileting problems (for example, bed wetting, soiling, and toilet training), tic and habit problems (like hair pulling, skin picking) and behavior problems in young children (such as tantrums, noncompliance, bedtime and sleep issues). He also provides care to children with more complex behavioral challenges, including severe defiance/noncompliance, aggression, self-injury, anxiety, and other similar difficulties. Emphasis is on practical, goal-oriented approaches designed to address presenting problems. Dr. Freeman is the lead psychologist for STAIR 7001 at OHSU, performing behavioral evaluations for the OHSU study visits.

**Dr. Andy Jones:** Dr. Andy Jones is the Poet Laureate of Davis. A longtime faculty member at UC Davis, Dr. Andy hosts a radio show, chairs the Cultural Action Committee of the City of Davis, and has given over 500 public talks and performances. His most recent book is titled Where’s Jukie? Find him online at www.andyojones.com.

**Dr. Chung Lee:** Dr. Lee is Assistant Professor in the Department of Molecular & Medical Genetics at OHSU. She is a Biochemical Geneticist who recently joined the OHSU SLOS research team and has already participated in study visits.

**Dr. Semone Myrie:** Dr. Myrie, RD, PhD is an Assistant Professor in the Department of Human Nutritional Sciences at University of Manitoba. She has worked with the STAIR group for the past 8 years, and has been overseeing the analysis of whole body cholesterol absorption, synthesis, and pool size for the STAIR study. She is the lead investigator in the study of nutritional intake in children with SLOS and is interested in the nutrition of mothers with children with SLOS as a potential modulator of SLOS clinical presentation (Dr. Myrie’s travel plans are not finalized).

**Dr. Mina Nguyen-Driver:** Dr. Nguyen-Driver is a licensed pediatric psychologist at the Child Development Rehabilitation Center (CDRC) at OHSU. She is an Associate Clinical Professor of Pediatrics and provides psychodiagnostic and neuropsychological evaluations to assess ADD/ADHD, Learning Disability and more. Dr. Nguyen also has specialty in infant testing. She is a co-investigator on several metabolic studies at the CDRC. Currently, Dr. Nguyen’s focus is on the cognitive and adaptive behavior functioning of children with Smith-Lemli-Opitz Syndrome.

**Gretchen Noah:** Gretchen Noah is the President and Treasurer of the Smith-Lemli-Opitz Foundation. With her husband Mark and their five children, Gretchen hosts annual fundraisers to benefit the foundation, and together these events have raised over $250,000 for research into Smith-Lemli-Opitz syndrome. Gretchen has worked as a CPA for Ernst & Young and has started a number of small businesses. Gretchen currently works as a donor relations associate for Concordia College in Moorhead, Minnesota. Gretchen and Mark are parents to Maggie 18, Kelly 16, Mary 15, Markie SLO 11, and Katie 10.
Dr. William Rizzo: Dr. Rizzo is a geneticist and professor with the Division of Inherited Metabolic Diseases at the University of Nebraska Medical Center. He is also affiliated with Children’s Hospital and Medical Center. Dr. Rizzo’s research interests include following patients with Sjögren-Larsson Syndrome and is the new principal investigator for the overarching STAIR Consortium. Dr. Rizzo’s clinic in Omaha, NE is one of the 4 STAIR 7001 study sites.

Dr. Jean-Baptiste Roullet: Dr. Roullet is a clinical professor in the department of Experimental and Systems Pharmacology at Washington State University College of Pharmacy in Spokane, WA, and an Affiliate Research Associate Professor at the Knight Cardiovascular Institute at OHSU. Dr. Roullet is a pharmacist and biochemist trained in laboratory medicine. Formerly co-principal investigator of the STAIR consortium with Dr. Steiner, he now serves as Administrative Director of the consortium with Dr. Rizzo. His research interests include rare diseases caused by disorders of the sterol and isoprenoid pathway, autism and stem cell research. Dr. Roullet is the STAIR 7001 study acting principal investigator and the OHSU site PI for the study. He serves on the Smith-Lemli-Opitz Foundation Medical Advisory Board and, along with Dr. William Rizzo, has been instrumental to the STAIR consortium receiving their second 5-year round of federal funding.

Dr. Robert Steiner: Dr. Steiner serves as the Executive Director of Marshfield Clinic Research Foundation in Marshfield, WI. Dr. Steiner is a medical geneticist who treats children with rare, inherited metabolic diseases such as phenylketonuria (PKU) and Smith-Lemli-Opitz Syndrome. Dr. Steiner is considered one of the leading experts on Smith-Lemli-Opitz Syndrome and is the Chair of the STAIR 7001 Study.

Dr. Audrey Thurm: Dr. Thurm is a child clinical psychologist and staff scientist at the National Institutes of Health Pediatrics and Developmental Neuroscience Branch. Dr. Thurm’s research focuses on autism spectrum disorders and other neurodevelopmental disorders with early onset, with interest in early diagnosis and predictors of outcome.

Dr. Elaine Tierney: Dr. Tierney is a research scientist and director of the Department of Psychiatry at Kennedy Krieger Institute. She is also an associate professor of psychiatry at the Johns Hopkins University School of Medicine. Dr. Tierney has a special interest in autism, genetic, metabolic and neurological disorders that cause behavioral disturbances. Dr. Tierney’s research has provided key insights in the link between low levels of cholesterol and autism spectrum disorders (ASD). Dr. Tierney directs the Autism Metabolic Research Program. This program, in coordination with the Kennedy Krieger Center for Genetic Disorders of Cognition and Behavior, investigates the presentation of ASD in individuals having metabolic disorders, including Smith-Lemli-Opitz Syndrome.

Dr. Anne Tsai: Dr. Tsai is a dysmorphologist and a clinical geneticist. She specializes in caring for children with birth defects, developmental concerns and family history of rare and inheritable diseases. Dr. Tsai sees Smith-Lemli-Opitz patients at Oregon Health & Science University.

SLO/RSH Foundation Board
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Kathy Proudfoot (UK), Director of Global Relations
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