



2014 NPKUA Conference Agenda

Thursday, July 10

- 8:00 Vendor set up, Foyer
- 12 noon Registration Opens, Foyer
- 2:00 Conference Exhibits Open, Foyer
- 6:00 Welcome reception at The Leonardo

Friday, July 11

- 8:00 Breakfast, Grand Ballroom
- 8:30 Welcome and NPKUA Update , Amy Oliver and Christine S. Brown, Grand Ballroom
- 9:00 Power of Rare Disease Community, Ronald J. Bartek, Friederich's Ataxia Research Alliance, Grand Ballroom
- 10:00 Medical and Dietary Guidelines for PKU, Dr. Cary Harding and Kathleen Huntington, RD, Grand Ballroom
- 11:15 Break, Foyer
- 12:00 Lunch (special seating for adults and teens), Grand Ballroom
- 1:30 Teen Grocery Store Tour, Lobby
- 1:30 NPKUA Funded Research, Grand Ballroom
- The Effects of PKU on Gray Matter Structures in the Brain, Dr. Shawn Christ, University of Missouri
 - Artificial Organ System by Encapsulating HegG2 Cells, Dr. Donna Santillan, University of Iowa Hospitals and Clinics.
 - Non-Physiological Amino Acid (NPAA) Therapy in Phenylketonuria, Dr. K Michael Gibson, Washington State University

- Liberalization of the Dietary Restrictions for PKU Patients: LNAA Supplementation in PKU Mice, Dr. Eddy A. van der Zee, University of Groningen

4:00 Scientific Poster Session and Vendor Displays, Canyon B and Foyer

7:00 Evening Free Time; Dinner on your own
The Pheast: PKU Teen and PKU Adult Low Protein Dinner for ages 15+, spouses welcome at The Founders Room

Saturday, July 12

8:00 Breakfast, Grand Ballroom

8:30 NPKUA Home Phe Monitor Development and Research Challenge, Dr. Tom Franklin
Report of NPKUA Scientific Exchange Session, Dr. Cary Harding, Grand Ballroom

9:15 Breakouts

- New Parent Session, Dr. Harvey Levy, Fran Rohr, RD and Christine Brown, Granite
- Genes for Teens, Karin Dent, MS, CGC, Salon 2
- Adult Management: Amy Cunningham, RD and Kathleen Huntington, RD, Salon 1
- PKU and Neurocognition, Dr. Kendra Bjoraker, Seminar Theater
- What Does Successful PKU Management Look Like?, Dr. Longo and Dr. David Dimmock, Canyon A
- Maximizing Nutrition in the PKU Diet, Sharon Ernst, RD, Canyon C
- Medical Foods Coverage and Advocacy, Amy Oliver, JD and Kristen Vanags, Salon 3

10:45 Break, Foyer

11:00 Breakouts

- PKU in the School Years, Ashley Vollenweider, NP, Krista Viau, RD and Jon and Melissa Baker, Granite
- Staying on Diet in the Teenage Years, Fran Rohr, RD and Laurie Bernstein, RD, Salon 2
- Adult PKU Session – Research Summary, Mike Franklin, Salon 1
- PKU and Neurocognition, Dr. Kendra Bjoraker, Seminar Theater
- How Much Phe? On-line Food List, Virginia Schuett, Sarah Chamberlain and Jeb Haber, Canyon A
- Maximizing Nutrition in the PKU Diet, Sharon Ernst, RD, Canyon C
- Insurance Coverage Workshop, Raenette Franco, Salon 3

12:30 Lunch, Grand Ballroom

- 1:30 Breakouts
- a. Creating PKU Awareness and Events in Your Community, Panel: Lisa Veleff Day, Bonnie Brady, Heather Bomar and Sherry Markwell
 - b. Teen Esteem: Feeling Good about PKU through the Teenage Years, Salon 2, Fran Rohr, RD and Laurie Bernstein, RD
 - c. Maternal PKU, Amy Cunningham, RD , Salon 1
 - d. How to Make the New PKU Guidelines Work for You, Dr. Dimmock and Kathleen Huntington, RD, Canyon A
 - e. Cooking for the PKU Diet, Panel: Sara Tye, Kevin Brown, Lynn Paoella, Seminar
 - f. Exchange of Tips in Managing PKU Daily: NPKUA Board Members, Canyon C
- 3:00 Free Time
- Hiking in Memory Grove
Tour of Temple Square
City Creek Shopping
Children's Museum
The Planetarium
Chill Out with PKU Teens and Adult: Walk to Gateway and DQ
- 5:30 Vendor Displays and Cocktail Hour, Promenade and Foyer
- 6:30 PKU Hero Award Banquet, Grand Ballroom
Honoring Dr. Harvey Levy, Senior Physician in Medicine and Genetics, Children's Hospital Boston and Professor of Pediatrics, Harvard Medical School

Sunday, July 13 (morning)

- 8:30 Breakfast, Grand Ballroom
- 9:00 NPKUA Funded Research, Grand Ballroom
- Liver cell transplantation, Dr. Kristen Skvorak, University of Pittsburgh Medical Center
 - Genetically Engineered Probiotics, Katherine Deming, University of North Texas Denton
 - Effect of PKU on the Gut Microbiome and Implications for Probiotic Therapy, Dr. Michael Allen, University of North Texas, Fort Worth
- 10:00 PKU Panel: Dr. Harvey Levy, Kathleen Huntington, RD, Mary Brown, RD, Christine Brown, Leah Kanihan; Facilitated by Amy Oliver, JD
- 11:30 Closing, Grand Ballroom