



2018 NPKUA Conference Agenda

Thursday, July 5

- 12:00 Registration Opens, Foyer
- 12:00-4:30 *Register for the PKU Registry & Advocacy Information*
- 2:00 Conference Exhibits Open, Foyer (Available at lunches, breaks and prior to banquet)
- 6:00-9:30 Welcome Reception at the Atlanta Botanical Garden

Friday, July 6

- 8:00 Breakfast
- 8:45 Welcome & NPKUA Update
- 9:30 History of PKU
- 10:30 Future of PKU
- 11:15 International Association Introduction
- 12:30 Lunch
- 1:30 Patient Registry Update
- 2:00 Clinical Trials Panel Discussion
- 3:30-5:30 *Register for the PKU Registry & Advocacy Information*
- 4:00 Scientific Poster Session, Networking and Vendors
- 6:00 Evening Free Time; Dinner on your own
- 6:00 The Pheast: PKU Teen and PKU Adult Low Protein Dinner for ages 15+, spouses welcome, (pre-registration required)

Saturday, July 7

- 8:00 Breakfast
- 8:30 Adult and Teen Panel Discussion – Q&A
- 9:30 Breakouts
- a. Parent Topic - Newborns and Toddlers
 - b. Adult Topic – Returning to Diet on a Budget
 - c. Teen Topic – Peer Pressure (Explaining PKU to friends, eating out)
 - d. Research Topic
 - e. Caring for yourself as a Caregiver
 - f. Advocating for PKU
 - g. Strategies to Shake Off Diet Related Anxiety
 - h. PKU and Neurocognitive Development
- 10:45 Break, Foyer
- 11:00 Breakouts
- a. Parent Topic – Life Coach Training ‘Coaching to motivate children’
 - b. Adult Topic –Weight Control and Exercise
 - c. Teen Topic – Transition to College and Adult Life
 - d. Research Topic
 - e. Healthy Flexi-phe Meal Planning for the Entire Family
 - f. Fundraising – LTL update, importance and small fundraisers
 - g. Meal Planning with Schools
 - h. Siblings –non PKU children helping siblings with PKU....but not overdoing it
- 12:30 Lunch
- 1:30 Breakouts
- a. Parent Topic – School aged kids -Self-care/ Self-Management Skills (Formula, blood draws, count phe, and tips)
 - b. Adult Topic – Maternal PKU
 - c. Teen Topic – Overcoming Obstacles – Sports & Beyond
 - d. Research Topic
 - e. PKU and Neurocognitive Development
 - f. Why Local PKU Orgs are important – we need you!
 - g. Resources and Strategies for an Easy and Tasty PKU diet: How Much Phe and Cook for Love
 - h. Grandparent Topic
 - i. Virtual Grocery Tour
- 3:00 Free Time/Vendor Displays

- 3:00-4:30 Virtual Grocery Tour- will be open to providing shopping tips, sampling and other information until 4:30 PM
- 3:00-4:30 PKU Member Organizations – information and Q&A
- 3:30-5:30 *Register for the PKU Registry & Advocacy Information*
- 5:30 Vendor Displays and Cocktail Hour/Networking Time
- 6:30 PKU Hero Award Banquet

Sunday, July 8 (morning)

- 8:00 Breakfast
- 9:00 Panel Discussion with Funded Researchers
- 10:30 Home Phe Monitor Update
- 11:00 PKU Therapies and Development
- 12:00 Closing/Exhibit take down

Please pick up children from Kids Zone immediately following conference closing.