



## 2018 NPKUA Conference Agenda

### Thursday, July 5

- 12:00 Registration Opens, Foyer
- 12:00-4:30 *Register for the PKU Registry and Advocacy Information*
- 1:00-3:00 *Insurance Coaching Program Available*
- 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 Panel Discussion with NPKUA Funded Researchers
- 3:30-5:30 *Register for the PKU Registry and Advocacy Information*
- 3:30-5:30 *Insurance Coaching Program Available*
- 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 age's 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
- i. Member Organization Fundraising

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. Family 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
- i. Inborn Errors of Metabolism Stakeholder Network

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
- 3:00-5:30 Register for the PKU Registry and Advocacy Information*
- 3:00-5:30 Insurance Coaching Program Available*
- 5:30 Vendor Displays and Cocktail Hour/Networking Time
- 6:30 PKU Hero Award Banquet

Sunday, July 8 (morning)

- 8:00 Breakfast
- 9:00 Clinical Trials Panel Discussion
- 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.**