



## 2018 NPKUA Conference Agenda

### Thursday, July 5

- 12:00 Registration Opens, Foyer
- 12:00-4:00 *Register for the PKU Patient 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
- 8:30 Drop off children at Kids Zone
- 9:00 Welcome & NPKUA Update
- 10:00 History of PKU
- 11:00 Future of PKU
- 11:45 International Association Introduction
- 12:00 Pick up children at Kids Zone
- 12:15 Lunch
- 1:00 Drop off children at Kids Zone
- 1:15 Patient Registry Update
- 1:45 Panel Discussion with NPKUA Funded Researchers
- 3:00 Home Phe Monitor Update
- 3:30-5:30 *Exhibits and Register for the PKU Registry, Advocacy Information Q & A*

- 3:30-5:30      *Insurance Coaching Program Available*
- 4:00            Scientific Poster Session, Networking and Vendors
- 5:30            Pick up children from Kids Zone (*Kids Zone closed for the day*)
- 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            Drop off children at Kids Zone
- 8:45            Adult and Teen Panel Discussion – Q&A
- 9:45            Breakouts
- a. Parent Topic - Empowering vs. Enabling
  - 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
- 11:15          Breakouts
- a. Parent Topic – Newborns and Toddlers
  - 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
  - i. Make Your Voices Heard!
- 12:15          Pick up children from Kids Zone
- 12:30          Lunch
- 1:15            Drop off children at Kids Zone

- 1:30 Breakouts
- a. Parent Topic – Picnic Table Talk
  - 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 Pick up children from Kids Zone (*Kids Zone closed for the day*)

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, Advocacy Information and Insurance Q & A*

5:00 Vendor Displays and Cocktail Hour/Networking Time

6:00 PKU Hero Award Banquet

Sunday, July 8 (morning)

8:00 Breakfast

8:30 Drop off children at Kids Zone

8:45 PKU Therapies and Development

10:45 Clinical Trials Panel Discussion

12:00 Pick up children from Kids Zone (*Kids Zone closes immediately following conference close at 12:00*)

12:00 Closing/Exhibit take down