



2021 NPKUA Mini-Conference Agenda

Day 1 (CST) - Friday, July 9, 2021

Kids Zone (all ages) 1:00-5:30 pm available –entertainment and fun

1:00-1:30 pm **Welcome and a Report on the NPKUA**

Amy Oliver, NPKUA President, and Christine Brown, NPKUA Executive Director, will provide you with a warm welcome and share all of the new and continuing work of the National PKU Alliance in moving research, support and public policy forward to serve the community.

1:30-2:30 pm **PKU Chat in a Snap**

Join adults, Brittany Holmes, APRN; Matt Mounger; Lilly DeCamilla, and teens, Connor Brown and Ally Hall, with a Q&A chat about life experiences with PKU, led by Amy Oliver, NPKUA President.

2:30-2:45 pm **Break**

2:45-3:15 pm **The PKU Patient Registry, Bringing the Patient Voice to PKU Research**

Lauren Youngborg, NPKUA Patient Registry Director, will provide highlights of the PKU Patient Registry and discuss how important and easy it is for patients and caregivers to participate. Hear from real registry participants and even have the opportunity to win a prize!

3:15-4:15 pm **Breakout Sessions:**

1. Pegvaliase; The Who's, the How's and the Now

Dr. Stephanie Sacharow will provide an overview on her experiences with over 50 patients in the PAL Clinic at Boston Children's hospital. Topics include time to efficacy, side effects, creative dosing, and diet changes.

She will be joined by Lauren Read, an adult with PKU, and we will leave time for questions and discussion.

2. Just for Teens – Game Time!

Get ready for a mind-bending experience! The Mind Games SmartHunt® is designed to push your mental limits and inspire out-of-the-box thinking. Participants will enjoy a series of optical illusions, riddles, and trick-questions that will expand their understanding of reality. Creative thinking, logic, and memory skills will be put to the test while everyone tries to rack up as many points as possible to show off their intellect!

3. We've Got You Covered! Resources for New PKU Families

Christine Brown, NPKUA Executive Director, will provide an overview of resources provided by the National PKU Alliance, NORD, information about PKU local organizations and resources by industry partners. Sarah Chamberlin, PKU News Executive Director, will walk new parents through how to access vital dietary-management resources such as How Much Phe: The Baby Book, HowMuchPhe.org, and Cook for Love's low-protein recipes. Sandy van Calcar, PhD, RD, LD, OHSU Registered Dietitian and Assoc. Professor, and Leah Bjornskov Wessenberg, RN, MN, FNP-C, OHSU Nurse Practitioner, will provide an overview of information and resources available at medical and genetic clinics.

4. Meet your Brain's Air-Traffic Control Center: Prefrontal Cortex and Executive Functions

Kendra BJORAKER, PhD, LP, a neuropsychologist, will present a summary of executive function skills or cognitive processes of action, thought, and emotions. She will discuss basic neuroanatomy of the prefrontal cortex (your brain's air-traffic control center) and provide an overview of specific interventions or accommodations to improve executive function skills. These skills are essential for building life-long core capabilities in managing tasks of daily life while at home, work or school, and in relationships.

4:15-4:30 pm **Break**

4:30-5:30 pm **Time for Networking!** *Please select the appropriate group that will maximize your engagement with others.*

Adults with PKU– Led by Lauren Read, PKU adult

Teens with PKU– Led by Melissa Goulhart, PKU adult

Parents & Grandparents of PKU Kids– Led by Heidi Maxfield, PKU parent

Industry/Sponsor Reps– Led by Tracy Fossum, NPKUA Director of Development

Medical Professionals & Researchers – Led by Lex Cowsert, NPKUA Director of Research Development

5:30-6:00 pm **Break and Prep for Happy Hour**

6:00-7:00 pm **Awesome Happy Hour**

Join in for the fun! You can learn how to mix up our featured drink and make a delicious low-protein snack lead by Kevin Brown, Chef and PKU Dad.

Day 2 (CST) – Saturday, July 10, 2021

8:30-9:15 am (Optional Registration) Yoga to Get Your Mind and Body Moving

Julie Kelly-Smith, an E-RYT® 200, RYT® 500, YACEP® yoga instructor and adult with PKU, will lead you in a morning yoga session that will stretch your muscles, heighten your senses, and help you to feel invigorated for today's conference session. This is a class for all levels and ages.

9:30-10:30 am Patient Champions Driving Research Forward

Lex Cowsert, Director of Research Development, will facilitate a discussion with Ryan Hollack, who participated in a clinical trial for gene therapy in hemophilia and Dan Peterson, who participated in a clinical trial for pegvaliase in PKU. Learn more about current clinical trials for PKU and how to get involved.

10:30-11:30 am Update on Gene Therapy for PKU - Ongoing Clinical Trials and New Approaches for the Future

Dr. Cary Harding, NPKUA Scientific Advisory Board Co-Chair and funded researcher at the Oregon Health & Science University, will provide an overview of how gene editing and therapy are on the horizon to treat PKU. He will provide an update on the progress of his research at OHSU and ongoing clinical trials and new approaches for the future.

11:30-11:45 am Break - Note: Conference Game Ends at 11:45 am

11:45 am – 12:15 pm “This is Our Year! Be a Voice for PKU!”

Kylie Barber, Medical Foods Policy Associate, will provide a Medical Nutrition Equity Act 2021 Update and prepare you for Rare Disease Week 2021 so you can help us pass medical foods coverage for all families in the U.S.

12:15 -12:30 pm Closing remarks

12:30 Visit Virtual Exhibits & Watch Recordings

Exhibitor area will be open prior to the conference and one week following the conference. Attendees can visit the virtual booths outside of the NPKUA planned agenda items.