

PKU Pulse Newsletter July 2025



This Month's Feature: Summertime is here! While we know you might still be working, we hope you get some vacation time, too. In this issue, we're talking about thriving with PKU at work and while traveling. Continue below for tips from Sophia and Nicole, who both live with PKU.

-The PTC PKU Pulse Team

Navigating the Workplace with PKU



Managing work, life, and PKU offers unique opportunities to showcase resilience and adaptability.

Learning to handle PKU at work may help open doors to strong careers and lives. We spoke with Sophia, who lives with PKU and works at PTC Therapeutics, to share her experiences and practical tips for getting through the professional world with confidence and success.

Shining a Light Through the Brain Fog

PKU can make your brain feel fuzzy. It can make it hard to focus, remember things and plan. This can make work more difficult.^{1,2} For Sophia, having a daily self-care routine is critical to control these effects:



Mental toughness requires getting enough sleep, eating well, exercising, and balancing work with stress-reducing activities.

– Sophia, living with PKU

From Challenges to Professional Strengths



Having special dietary needs offers a chance to raise PKU awareness. If you're comfortable doing so, share your journey with colleagues, introduce friends to new foods, and turn everyday work moments into educational opportunities.



Skills developed through PKU management - such as discipline and organization - translate directly to the demands of a professional environment.

Celebrate your adaptability and the creative solutions you bring to the table.

Approaching Meals at Work

Navigating meals at work requires flexibility and awareness. Sophia brings lunch to work most days. When work provides free lunches to employees, she tells her coworkers what foods she can eat.

While she chooses to share her experience with PKU publicly, she understands that others may prefer to keep it private. Sophia says you can ask for a vegetarian option, and this helps to be able to enjoy a meal with your team without problems.





The most helpful advice I received from my dietitians, physicians, and nurse practitioners related to managing PKU in the workplace was that by managing my Phe levels would help me in my day-to-day work. My advice to anyone coming into the workforce is to rely on your clinic; they are in your corner and will be your biggest advocates.

– Sophia, living with PKU

Clocking In: Advice for Young Adults Entering the Workforce

It's important to focus on careful meal planning and lean on those around you for support. Balancing work and PKU can come with challenges but finding the right balance that fits your needs is crucial.





Embrace disciplined diet management and look for support from your clinic, family or support system. Everyone's PKU journey is unique and personal, so find what works best for you. PKU should not hold anyone back. Dream big, shoot for the stars, and believe in yourself.

– Sophia, living with PKU

Planes, Trains, & Phe-Friendly Meals

Whether you're vacationing or heading out on a business trip this summer, check out these PKU-friendly tips for smooth travels from Nicole, a travel nurse who lives with PKU:



Air Travel Essentials

Bring a letter from your doctor that explains the importance of your medical formula. Remember, security typically just scans the formula, so don't panic if your bag is pulled aside!



Packing for Longer Trips

Use the "two eyes check" method before leaving. Nicole always has someone else count and pack her formula with her to avoid forgetting it.



Exploring New Places

Look up restaurants before you go. Call them with questions. Nicole says most restaurants will help when you tell them what you can eat.



Travel is about exploring and creating memories, not just food. Embrace the adventure and remember that perfection isn't necessary. Learning from challenges enhances the journey and your personal growth!

– Nicole, living with PKU

News You Can Use

A team of PKU experts from Boston Children's Hospital, recently conducted [a study](#), led by Suzanne Hollander and Stephanie Sacharow, M.D., aimed at understanding why many adults with PKU became disconnected from clinical care and how to improve patient engagement.

The study included both individuals actively engaged with their local clinic and those who had lost touch with PKU care. The researchers utilized moderated focus groups to gather insights.

Participants expressed a strong desire for³:



Better communication

Enhanced support and access

Stronger community connections

Scroll down for events and more ways to broaden your support network and community connections!

flok wants to bring people with inborn errors of metabolism together. They work to make care better and help research move faster. Every year, flok Family Camps bring together the PKU community for multiple days of traditional camp fun, crafts, educational sessions, and delicious low-protein meals.

Check out these photos from Family Camp West!



Register for Family Camp East (September 18-21)

Upcoming Events

July 2025



July 26 PKU in the Park

Hershey, PA

[JOIN NOW](#)



July 26 CCPKUAD Family Day

Atascadero, CA

[JOIN NOW](#)



July 30 NECPAD Water Wizz

Boston, MA

[JOIN NOW](#)

August 2025



August 9 PTC Listening Session/Cooking Demo with Iowa PKU Foundation

Cedar Rapids, IA

To RSVP, contact
ehintze@ptcbio.com



August 24 PKU Hope Gala

Middleburg, VA

[JOIN NOW](#)



August 25 PKU Hope Golfing Outing

Aldie, VA

[JOIN NOW](#)

Stay connected for more PKU news, tips, and community stories by following Reimagine PKU!





References:

1. Ford S, O'Driscoll M, MacDonald A. Living with Phenylketonuria: Lessons from the PKU community. *Mol Genet Metab. Rep.* 2018;17:57-63. Published 2018 Oct 18. doi:10.1016/j.ymgnir.2018.10.00b
2. Bilder DA, Noel JK, Baker ER, et al. Systematic Review and Meta-Analysis of Neuropsychiatric Symptoms and Executive Functioning in Adults With Phenylketonuria. *Dev Neuropsychol.* 2016;41(4):245-260. doi:10.1080/87565641.2016.1243109
3. Zhu E, Hollander S, Sacharow S. Patient voices on PKU core: Insights from focus groups with current and former patients. *Mol Genet Metab.* 2024;41:101148. doi:10.1016/j.ymgmr.2024.101148