

This Month's Feature:

With the start of a new school year upon us, this month's newsletter focuses on tips for helping students living with PKU and caregivers feel more prepared when navigating school environments. Whether you're a parent preparing a young child for school, a teen gaining independence, or an adult navigating college or continuing education, planning ahead can help ensure PKU needs are understood and supported.

-The PTC PKU Pulse Team

Back-to-School with PKU: Set Up for Success



Navigating PKU in educational settings can feel overwhelming. However, with the right planning and communication, families can set up children and young adults for success at every stage. Below, check out helpful tips for parents of children living with PKU, whether sending little ones to daycare for the first time or prepping for college transitions.

- **Start early:** Initiate discussions with school administrators and food services staff about dietary needs and expectations before the school year begins
- **Establish support:** Request review of the 504 plan for dietary and medication needs annually to ensure access to medical formula consumption in the classroom, low-protein foods, and medication during the school day
- **Build your team:** Work closely with metabolic dietitians, school staff, or campus health or disability services to coordinate support
- **Think beyond the classroom:** Connect with coaches, activity leaders, and counselors to maximize support



"As a parent of a child with PKU, you are their strongest advocate when it comes to navigating PKU at school. When you build a team that includes their teachers, counselors, coaches, dietitians, and campus services, you're creating a path where your child can participate fully and thrive, from preschool through college."

Natalie Beall, RDN
Patient Engagement Liaison, PTC

"With a little preparation, like early conversations with administrators and food services, a clear plan for meals and formula, and the right accommodations, your child with PKU can feel included, confident, and supported at every grade level. You've got this!"

Sommer Gaughan, MPH, RD
Patient Engagement Liaison, PTC



No matter the age or setting, thoughtful preparation and ongoing communication can make a meaningful difference for children with PKU.

Community Champions

[The PKU Organization of Illinois](#) has served as a vital resource for individuals and families affected by PKU and allied disorders for decades. Founded in 1969 by parents and medical professionals, the organization was built on a shared commitment to support the PKU community, and that mission remains unchanged today. By providing resources, education, and a strong sense of connection, the organization supports individuals with PKU at every stage of their life, ensuring everyone feels seen and empowered.

The PKU Organization of Illinois creates meaningful opportunities for connection through initiatives and community-driven programs like Move Your Pheet, Family Fun Day, and the Illinois Low Protein Family Camp. PTC has the privilege of being one of the sponsors for the Family Camp, which helps provide valuable access to PKU resources and low protein food, while enjoying fun camp activities.



Emily Hintze, Patient Engagement Liaison and Rupert Evans, Regional Account Manager from PTC at the Low Protein Family Camp.

Upcoming Events



October 2026

Navigating PKU™ Local Events

- Check out the Navigating PKU™ website for events in your area
- If you don't see an event near you, request a program on the website linked below

[CLICK HERE](#)



October 4

New England Connection for PKU and Allied Disorders (NECPAD): HoneyPot Hill Applefest

- Stow, MA
- For more information, check out NECPAD's website

[CLICK HERE](#)



October 10

National PKU Alliance: Lifting the Limits for PKU

- Philadelphia, PA
- For more information, check out the NPKUA website

[CLICK HERE](#)



October 10

Alliance of PKU Families: PKU in the Park at Busch Gardens

- Williamsburg, VA
- For more information or to register, check out Alliance of PKU Families' website

[CLICK HERE](#)



October 25

New England Connection for PKU and Allied Disorders (NECPAD): Canobie Lake Screemfest

- Salem, NH
- For more information, check out NECPAD's website

[CLICK HERE](#)

Stay connected for more PKU news, tips, and community stories by following [ReimaginePKU!](#)

