

This Month's Feature:

October brings the opportunity to pause ahead of the holiday season and revisit everyday routines, goals, and healthy habits. We connected with Stephanie Hacker, Metabolic Dietitian, LDN, RDN, to discuss the best ways to support an active lifestyle and pursue athletic goals while living with PKU.

-The PTC PKU Pulse Team

Fueling Your Body: Advice for the PKU Community



How does exercise change protein needs when someone lives with PKU?

- There has not been much research on exercise and PKU, so there is no scientific consensus on the effect of exercise on protein needs for those with PKU. In the general population, exercise increases protein needs. However, in individuals with PKU, recommendations of where increased protein should come from need to be individualized. The timing of protein intake and ensuring adequate energy and carbohydrate intake is also important; individuals with PKU should work with their dietitian to determine the best timing.

What does a good pre-workout snack look like for those with PKU (especially if you're trying to add some natural protein)?

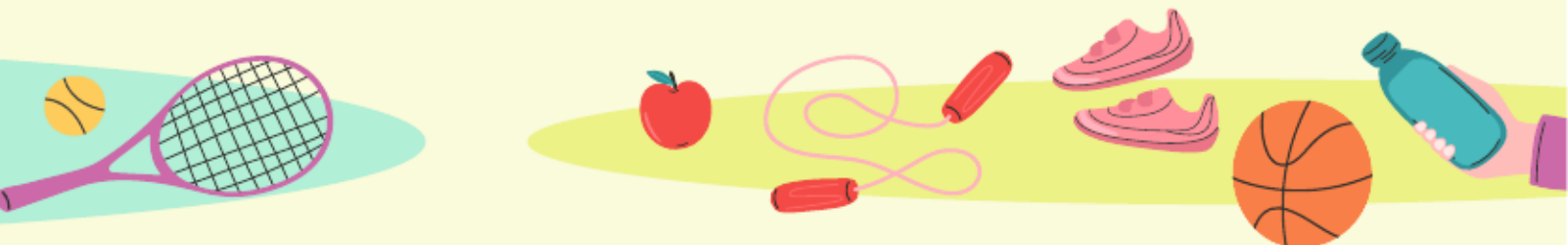
- Ideal pre-workout nutrition is generally carbohydrate forward and should be consumed 30 - 60 minutes before an activity. For those following traditional PKU management, pre-workout snacks can be fruit, low protein crackers/bread, a low protein granola/snack bar, or coconut yogurt. Individuals with PKU should talk to their dietitian to determine the best pre-workout snack for them.



Stephanie Hacker, Metabolic Dietitian, LDN, RDN

Are there special considerations for teens with PKU in sports?

- Adolescents with PKU are balancing puberty, increased demands (from school/activities) and higher protein needs, and greater independence with diet adherence. Additionally, they may be more active than they were when they were younger, particularly as participation in high school sports becomes more competitive. Lastly, families may start taking a back seat to their teens' PKU management, so they are having to learn how to gain more responsibility over making their medical foods, any prescription medication, and track their protein intake.



Community Champions

The [California Coalition for PKU & Allied Disorders](#) (CCPKUAD) is a volunteer-led organization dedicated to providing support, education, and advocacy for individuals and families affected by PKU and other inborn errors of metabolism (IEM). Founded in 1981 by PKU parents, the organization was formerly known as PKU Parents in California.

PTC was proud to support CCPKUAD's annual PKU Family Day event in Ventura, CA on Saturday, August 8. Earlier this year, PTC partnered with CCPKUAD to host a Navigating PKU program in Orange County where families learned about financial resources, insurance navigation, and available support services, featuring Soo Shim, LCSW.



Aurora Flores, Patient Engagement Liaison and Erin Canavan, Regional Account Manager from PTC at PKU Family Day.

Upcoming Events



November 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](#)



November 7

PKU Organization of Illinois: Low Protein Annual Meeting

- Virtual – Zoom
- For more information, check out the PKU Organization of Illinois' website

[CLICK HERE](#)



November 13

National PKU Alliance: Lifting the Limits for PKU

- Durham, NC
- For more information, check out National PKU Alliance's website

[CLICK HERE](#)

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

