PTC Reimagines PKU

PKU PULSE

NOVEMBER 2026 NEWSLETTER

This Month's Feature:

November is National Family Caregivers Month, a time to recognize the dedication and support that caregivers bring to their loved ones every day, from managing dietary routines and offering encouragement to helping navigate daily life with PKU. Thank you to all of the incredible PKU caregivers, whose dedication makes a difference every day. We hope you find time to rest and take care of yourselves this month as you continue to support those you love.

-The PTC PKU Pulse Team

Caring for the Caregiver: Building Resilience

We connected with Dr. Eugene Lubliner, Psy.D., BCBA, LBA, and PKU father, to discuss the importance of caregiver wellbeing, self-care, and the role of community in navigating PKU together.

What habits or mindset shifts can help PKU caregivers build resilience and manage the long-term challenges of PKU?
Dr. Lubliner: First and foremost, self-care is part of the treatment plan. You have to take care of yourself, and that has to be a major component when you're taking care of someone else. You also have to accept the fact that things are never going to be perfect. We don't want perfection. We want consistency. It's better to be really good for 10 straight days than be perfect for a single day. And you have to accept that mistakes are going to happen. There are a lot of factors out of our control, and we can acknowledge that, roll with those consequences, and adapt. If you approach it with that mindset, this whole process can become a lot easier.



Dr. Eugene Lubliner, Psy.D., BCBA, LBA
and his daughter, Addie, who lives with PKU
Dr. Lubliner is a paid consultant of PTC Therapeutics, Inc.

Why is connecting with the PKU community so valuable for caregivers?
Dr. Lubliner: I think it's always important for anyone that has this complex set of responsibilities to reach out and get social support. No one is going to understand the daily responsibilities and struggles of managing and caring for someone with PKU like another person that manages and cares for someone with PKU. So, reaching out, establishing that community, and having a set base of people to call and rely upon when you have questions (or you're just not feeling your best), can really help day-to-day.

What message would you like PKU caregivers to hear?
Dr. Lubliner: It's okay to acknowledge that caring for someone with PKU is challenging. It's okay to know that a lot of hard work is required, from managing and anticipating, to providing daily care. You deserve to be recognized for that work, and you're not alone.

Community Champions

Founded in 2024, PKU Alaska is a local nonprofit that supports individuals and families affected by PKU and helps raise funds for national PKU research and resources. The organization raises awareness of PKU and builds connection with Alaska's PKU community through advocacy, education, and family-centered events.

This May, PKU Alaska hosted its "Move Your Pheet" 5K walk, run, and post-event reception, which brought together community members for a walk/run and fundraising activities during National PKU Awareness Month. PTC was proud to join the community in support of this meaningful event.



Malisa Rust, Patient Engagement Lead, Metabolic,
from PTC at "Move Your Pheet."

Upcoming Events

December 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

December 3

Carolina Coalition for PKU and Allied Disorders: National PKU Awareness Day – PKU Pizza Party

- Multiple locations
- For more information, check out the Carolina Coalition for PKU and Allied Disorders' Facebook Page

CLICK HERE

December 5

Children's Wisconsin: Annual Low-Protein Patient Holiday Event

- Milwaukee, WI
- For more information, check out the Children's Wisconsin website

CLICK HERE

December 9

Alliance of PKU Families: Adult PKU Round Table

- Virtual
- For more information, check out the Alliance of PKU Families' website

CLICK HERE

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

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