PTC Reimagines PKU.

PKU Pulse Newsletter

November 2025

The holidays are here! We hope everyone enjoys this season of gatherings and special moments together. In this issue, we're sharing simple ways to navigate PKU around the holidays and highlighting people and moments we're thankful for.

–The PTC PKU Pulse Team

Holiday Talk: Sharing What PKU Means

With family gatherings, work parties, and holiday dinners, the season is filled with connections...and plenty of food. This can present opportunities to explain what PKU means to others. Some tips include:

Start with the Basics

Mother-daughter duo Pam and Kelsey, who both live with PKU, describe it to others as "a special diet," which may mean eating certain foods and drinking formula.

Break It Down

Sarah Chamberlin, Founder and Executive Director of flok and PKU mom, has a go-to line to explain PKU when asked about it. She shares that PKU is "when the body can't break down part of protein called phenylalanine and it builds up in their system and can act as a neurotoxin."

Talk It Through

Jenn Beazer, RDN, LD/N, Metabolic Dietician, advises people with PKU to think of a way to describe it quickly (30-60 seconds) and have a version with more detail when asking for work or school accommodations.

> *If you have a family member living with PKU, talk with them about how they may want to approach it in social settings. Sometimes people living with PKU are happy to share their experience. Other times, they want to blend in.*
>
> *- Matt, living with PKU*

Spotlight on the PTC *Cares* Team

PTC's Patient Support team, PTC *Cares*, supports families and people living with rare diseases, including PKU, by helping them navigate insurance and treatment access challenges and providing encouragement. This can be especially important during the busy holiday season.

To get to know the team better, here are a few fun facts from the people who bring this program to life:

- **Rachel Coleman** is a passionate reader who finishes 75–100 books a year.
- **Rick Rodriguez** collects vintage vinyl and loves jazz and hip-hop.
- **Bert Smith** once biked from Florida to New York, camping along the way.

- **Peter Apito** earned “Sportsman of the Year” for baseball in school.
- **Courtney Cruz** sews imaginative dolls that “add a touch of magic to everyday life.”
- **Kenneth Phung** is an identical twin—a surprise discovery for his mom!
- **Frances Hisle** enjoys drawing and recreating cartoon characters.
- **Sarah Sanchez** celebrated turning 30 by skydiving—an experience she’ll never forget!

To learn more, visit PTCCares.com or reach out to our team at 1-844-4PTC-CARES (1-844-478-2227), available Monday through Friday from 8 AM to 6 PM ET.

A Season of Thanks: Honoring PKU Caregivers

November is National Family Caregivers Month, and there’s no better time to thank families, friends, coworkers and everyone else who supports their loved ones with PKU.

Your compassion and dedication are the heart of this community.

PKU Awareness Day: Shining A Light

Every December 3, the PKU community celebrates National PKU Awareness Day, a time to shine light on what it means to live or take care of someone living with PKU. It's a time to remind others that small actions can make a big impact.

Below are a few ways people in the PKU community describe what this day means to them:

Help Others Understand: Tracy, living with PKU, believes that "when you advocate for yourself and your health," it helps others learn about PKU—both now and in the future.

Build Connection: Catherine Warren, Executive Director of the National PKU Alliance (NPKUA) notes that "awareness days are important to build a community and help share information with others who don't know about PKU."

Share Your Story: For Kurt, living with PKU, this day is a "reminder for people to share their experience on their own terms to find their voice."

Join the celebration by taking a moment to connect with others or share what National PKU Awareness Day means to you!

Connecting the World of PKU 2025

Last month, Connecting the World of PKU 2025 brought together experts, doctors, and advocates from across the world to explore new insights in PKU care and treatment.

Here are three takeaways from Ryan Miller, PTC Field Medical Lead for PKU:

- **A global community comes together:**
  The first-ever PKU Con was held in Hamburg, Germany to discuss all aspects of PKU.

- **New ways to support better health:**
  Sessions covered the latest treatment guidelines, strategies to prevent high Phe levels during stress or illness, and how current and future innovations in PKU management may help people with PKU live healthier lives.

- **Looking beyond Phe:**
  Experts shared ways to track people's health and discussed nutrition topics like low-protein foods, large neutral amino acids, and the role that nutrients play in memory and focus.

Upcoming Events

December 2025

December 1

Intermountain PKU and Allied Disorders Association (IPAD)

Community Program

Salt Lake City, UT

JOIN NOW

December 4-7

Camp Sunshine

Family Camp

Casco, ME

JOIN NOW

December 7

PTC Therapeutics

Navigating PKU Cooking Event

Detroit, MI

RSVP

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