

## This Month's Feature:

Gaining independence when living with PKU means learning how to prepare for life's milestones, big or small. From navigating social events or planning ahead for new experiences, these moments become opportunities to build confidence, advocate for personal needs, and practice the skills that support independent living with PKU. This month we explore how preparation and positive perspective can help individuals in the PKU community continue growing into their own routines throughout the various stages of life.

-The PTC PKU Pulse Team

## Stepping into Independence: Navigating Milestones with PKU

Preparing for milestones, whether it's a vacation, a special event, or dinner at a friend's house, has always required intention and flexibility for Amanda, who lives with PKU. She has shared that planning ahead has become second nature early on: connecting with hosts beforehand, asking about menus, and bringing her own low-protein foods when needed. Over time, this mindset helped her approach milestone moments without resentment. Instead, **preparation became a tool to protect her peace, allowing Amanda to stay present and enjoy her time in the moment.**



Amanda, individual living with PKU

Today, Amanda feels even more empowered living with PKU, thanks to modern conveniences like being able to check online menus in advance. She's also learned to **communicate openly** with friends before having a meal together, sometimes suggesting if they can make salad or potatoes, or offering to bring something herself. Through it all, Amanda continues to emphasize that keeping expectations realistic and embracing preparedness has been key to her PKU journey.

## Community Champions

[Asociación PKU de Puerto Rico](#) is a non-profit organization that provides services to children, youth, and adults with phenylketonuria. The group emerged as an initiative by parents of children with PKU and professionals who provide them with medical-nutritional services.

Their mission is to help those affected by PKU promote their health and well-being; advocate for better services; promote research regarding the condition; and establish a mechanism to make low-protein foods available and accessible in Puerto Rico.

On January 31, the first Navigating PKU™ program was held in Naranjito, Puerto Rico in collaboration with Asociación PKU de Puerto Rico. It brought together multiple individuals living with PKU and their families—along with local healthcare providers, representatives from the local specialty pharmacy, and PTC team members. Adelaida Segarra, a well-known pediatric registered dietitian, presented on eating well while living with PKU. This program gave the PKU community an opportunity to come together, share, connect, and learn.



Pictured above (left to right): Secretary of the Asociación PKU de Puerto Rico, Keyla Rios, Karina Lambertini, Sarah Sanchez, president of the Asociación PKU de Puerto Rico, Neida Vega, Navigating PKU™ speaker, Adelaida Segarra, RD, Eddie Cuellar, and Jennifer Roan.

*Navigating PKU is a trademark of PTC Therapeutics, Inc.*

## Upcoming Events



April 19

### Navigating PKU™: Low Pro Cooking with Jenn Beazer, MPH, RDN, LD

- 4-6pm CT
- Nashville, TN at Rose and Plum Living
- For more information and to RSVP, please contact: [patientengagement@ptcbio.com](mailto:patientengagement@ptcbio.com)



April 25

### Navigating PKU™: Acceptance of PKU Caregiver's Perspective

- Live/hybrid locations in Atlanta, GA, Michigan and New York
- For more information and to RSVP, please contact: [patientengagement@ptcbio.com](mailto:patientengagement@ptcbio.com)

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

