

# A Brighter Future.

That is what we promise the 15,500 Americans living with PKU.

In the last 50 years, the future for the PKU community has never been brighter. We work to continue that progress and help people with PKU live the best lives possible. Help us spread awareness of PKU and learn how you can support a cure.

## What is PKU?

PKU stands for Phenylketonuria, a rare brain threatening disease where your body can't process an amino acid called phenylalanine (Phe for short). Phe comes from protein-rich foods such as meat, eggs, nuts, beans, milk and cheese. Every newborn baby is tested for PKU by taking a blood sample and measuring the amount of Phe. Without early and continuous treatment, sustained high levels of Phe can cause severe intellectual disabilities. These disabilities can be prevented by controlling blood Phe levels by drinking a special medical formula free of Phe three times a day and following a strict low-protein diet, starting in the weeks after birth and continuing for life.

## What is the NPKUA?

Volunteer leaders created the National PKU Alliance in 2008 to serve a dual mission: improve the lives of individuals with PKU and pursue a cure. The signature program areas of the NPKUA are research, education, advocacy, and support. By bringing the collective experience of the PKU community to the table, the NPKUA is helping change the future of the disorder...how it will be known, how it will be experience, and how it will be cured.

## How Can you Help?

**Educate.** Know that there are many people living in the U.S. with rare diseases like PKU. 1 out of every 10 Americans has a rare disease.

**Support.** When you make a gift at NPKUA.org, you help support the most promising research projects aimed at accelerating the timeline for a cure, give thousands a better opportunity for insurance equity, provide support and education to new families and adults, and create a powerful voice for the PKU community.

**Advocate.** Contact your federal legislators and ask them to support reimbursement for medical foods treatment to cover the cost of treatment for PKU and similar diseases so children with PKU can grow up to be healthy and productive citizens.



National  
**PKU**  
Alliance



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