



# Support for Adults with PKU

## Finding and Programs

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The mission of the NPKUA is to improve the lives of people living with phenylketonuria and pursue a cure.



## HISTORY

- Founded in 2008
- Budget of \$1.8 million
- 5 full-time and 2 part-time professional staff
- Virtual organization
- Skill based Board of Directors
- Affiliate Council of state and regional PKU support groups



# KEY PRIORITIES

- Research
- PKU Care/Support
- Advocacy
- Awareness and Education



# ADULT PKU CARE/SUPPORT

- Emergency Food Assistance to 190 Pregnant Women
- 73 women have entered Maternal PKU Mentoring Program
- 16 affiliate organizations provide support at the local level







# PKU SUPPORT ACROSS THE LIFESPAN

Newborn Kit

NPKUA Conference Kids Zone





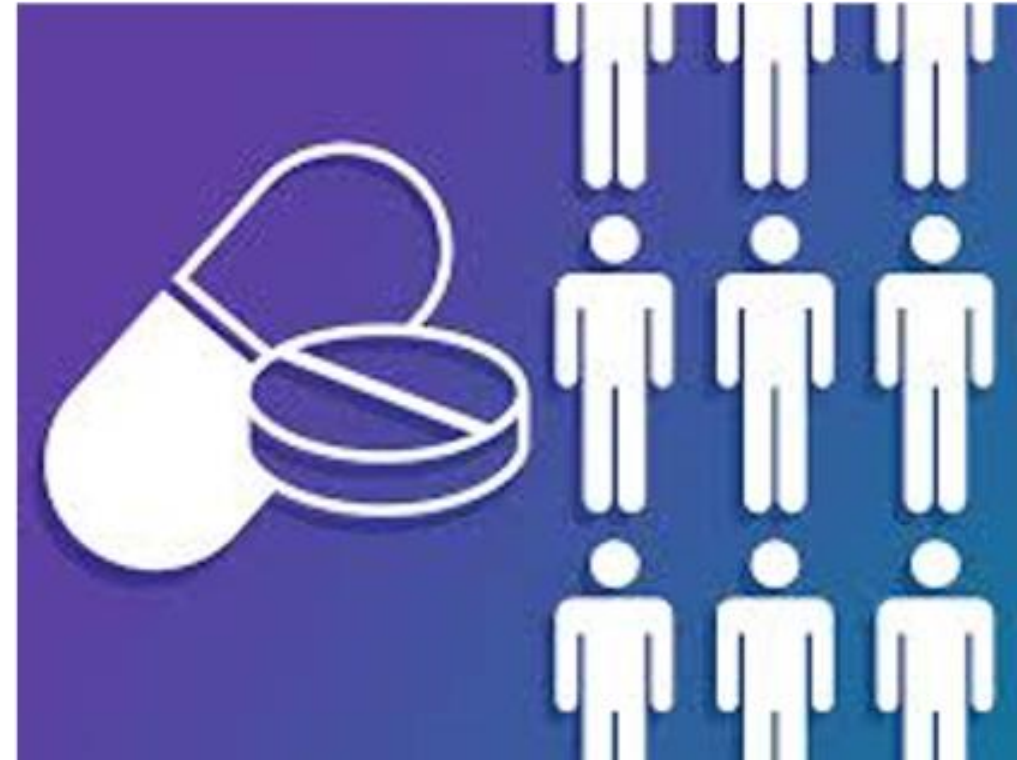
# PKU SUPPORT ACROSS THE LIFESPAN

NPKUA Conference: Adult Outing and Social

NPKUA Conference: Adult Breakouts

# ADULTS ARE STRUGGLING

- 16,500 Americans living with PKU
- 8,000 are in clinic and 8,500 haven't been seen in the last two years
- Coalition of industry partners working together to create targeted messages that it's never too late to return to treatment







# EXPANDING SERVICES TO ADULTS: RECENT SURVEY RESULTS

## Adults

- The single most important reason for not consistently maintaining their treatment were money, no motivation/willpower, inconvenience and availability of medical foods.
- The single most important thing they thought the NPKUA could do was creating mentorship opportunities, financial assistance, help with insurance and adult focused event.

## Clinics

- Indicated that most adults don't maintain treatment because of the time and energy needed to manage the diet.
- They indicated that poor executive function was the main barrier for adult patients.
- They agreed with the adults that the most important thing the NPKUA could do was focus on mentorship.

# PEER PROGRAM

- Nine trained adult mentors who have previously struggled with staying on treatment but feel they have it together now
- Provide emotional support and encouragement to adults with PKU who are currently off the low-protein diet and trying to get back in to managing their PKU better
- The power of a personal story and walking the same journey is meaningful and motivating





# PATHWAYS PROGRAM

- Nine trained volunteers
- Adults, parents/caregivers of PKU children
- Provide optimal executive functioning support for adults with PKU who have gone off the diet
- Virtual one-on-one assistance to meet them “where they are at”
- Help “connect the dots,” whether that be connecting adults to local and national resources, patient assistance programs with medical food companies, contacting a clinic, etc.





# PEER AND PATHWAY IMPLEMENTATION

- Call for volunteer applications in June/July
- Interviews and references in August
- 18 out of 30 applicants were chosen
- Virtual training in Oct/Nov
- Fully operational in December



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# THANK YOU

**CHRISTINE S. BROWN, EXECUTIVE DIRECTOR**  
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