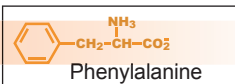


## ABOUT PKU



Phenylketonuria, commonly referred to as PKU, is a rare genetic disorder, occurring about once in every 12,000 births. People with PKU do not produce adequate amounts of the enzyme needed to metabolize the common amino acid, phenylalanine (or “phe”), which is part of the proteins found in most foods.

The only effective treatment for PKU is a diet that limits phenylalanine intake. Since phe is found in nearly all foods, the diet is quite restrictive but without it, phenylalanine accumulates in the blood and becomes toxic to the central nervous system. Infants with PKU can develop severe mental retardation and other physical problems if their phe intake is not strictly controlled.

Today, hospitals test all new babies for PKU and treatment is begun immediately after diagnosis. To ensure proper nutrition with a strict, low-phe diet, a special formula or medical food is necessary. PKU formulas are expensive but make it possible to maintain a diet that is low in phenylalanine while providing necessary energy, vitamins, and minerals.

In addition to formula, the diet for PKU can include limited amounts of some foods, specifically most fruits and vegetables, some cereals, and specially made low-protein breads, cookies, and pastas. All protein concentrated foods such as milk, meat, eggs, and cheese must be completely eliminated.

Lifelong treatment is critical for individuals with PKU to achieve and maintain full intellectual potential and physical development.



P.O. Box 95502  
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# PKU

## *Action Group*



The PKU Action Group, in cooperation with the University of Washington PKU/Biochemical Genetics Clinic, provides education and support to individuals and families living with phenylketonuria (PKU).

The PKU Action Group is a registered Washington State nonprofit corporation and is exempt from federal income tax under Section 501(c)(3) of the Internal Revenue Service code.

# The PKU Action Group



The PKU Action Group was formed in 1999 by parents of children with PKU. It is a volunteer organization with a board of directors comprised of parents of children with

PKU, professionals in the treatment of PKU, and others with varying professional expertise committed to supporting Washington's PKU community. Since its inception, over 95 percent of the funds raised by the PKU Action Group have gone directly into its programs and activities.

## PKU Action Group Activities

Managing PKU through diet is a lifelong commitment. Ongoing programs supported by the PKU Action Group provide different age groups with a variety of educational opportunities and assistance.

### **Family Outreach**

Starter kits with critical dietary management tools are provided to parents of Washington State newborns, including food scales, low protein cookbooks, and food lists (\$200 value).

### **Two Nationally Distributed Videos**

"Really Living with PKU" speaks to parents of newly diagnosed babies. It provides reassurance that with proper treatment, babies with PKU will grow up as healthy as any other child. "Maternal PKU: Choices You Can Live

With" informs women with PKU of the issues regarding pregnancy and potential risks to their unborn child. Copies of both these videos are available upon request and can be viewed at [www.pkupag.org](http://www.pkupag.org).

### **PKU Week at Camp Sealth on Vashon Island**

Camp tuition scholarships have been provided for Washington State children with PKU, ages 7 to 18. Campers can choose among a wide variety of camp experiences. Individual dietary needs are established and overseen by staff members from the University of Washington PKU Clinic in coordination with the camp staff.

### **Annual Science Night**

This educational event for parents and adults with PKU provides information on current research, new dietary products, and ongoing treatment guidelines. Parents and individuals have an opportunity to broaden their understanding of PKU in a social and non-clinical setting.



### **College Scholarships**

Established in 2004, the PKU Action Group scholarship program awards scholarships to graduating Washington State high school seniors with PKU, as long as they enroll at an accredited institution for post high school education or training.

### **Website**

The website [www.pkupag.org](http://www.pkupag.org) provides important information on PKU and the activities of the PKU Action Group.

### **PKU Action Group Endowment Fund**

The PKU Action Group is working toward establishing an endowment fund to ensure that their programs and services will continue to be available to Washington State's PKU community.



### **Find the PKU Action Group**

P.O. Box 95502  
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Phone: 206-685-3015  
Fax: 206-685-1286  
Email: [pkupag@pkupag.org](mailto:pkupag@pkupag.org)  
Web page: [www.pkupag.org](http://www.pkupag.org)

### **Other Resources**

University of Washington PKU Clinic  
<http://depts.washington.edu/pku>

National PKU News  
[www.pkunews.org](http://www.pkunews.org)

Children's PKU Network  
[www.pkunetwork.org](http://www.pkunetwork.org)

National Society for Phenylketonuria  
(British) <http://www.nspku.org/>