

What are AHD?

Allied Health Disorders (AHD) are inborn errors of the metabolism that can be similar to PKU. All the AHD require strict low protein diet. We support 16 allied disorders. More specific information can be found on our website, as well as links to larger specific AHD organizations. Our organization intends to identify resources, promote research, increase public awareness, and advocate for enhanced metabolic services within our state.



What is PKU?

PKU is an abbreviation for Phenylketonuria, an inherited amino acid metabolic disorder. PKU affects the amino acid, phenylalanine, which is one of the amino acids that are the building blocks of protein. In PKU, there is a defect in the chemical or enzyme that breaks down phenylalanine to another amino acid tyrosine. The liver enzyme that is affected is phenylalanine hydroxylase. PKU is a disorder that occurs with a wide range of severity. The average incidence of PKU worldwide is 1 in 15,000 births and the disorder can affect all genders, races, and cultures. A pioneer researcher in the early 1960s, Dr. Robert Guthrie, developed the first screening test for PKU. Prior to this test, most children with PKU developed severe mental retardation and many were undiagnosed. The good news today is that all the states in the United States and many countries throughout the world now screen for PKU at birth so the proper treatment can be started right away. While there is no cure, PKU can be treated by a strict low protein diet. The diet is needs to be followed the patients entire life. Illinois started their first newborn screening program in 1964 which is part of the Illinois Department of Public Health.

The PKU Organization of Illinois is affiliated with the following hospitals in Illinois:

Lurie Children's
University of Illinois Hospital Medical Center
Rush University Medical Center

We are a member of the **National PKU Alliance** that serves PKU patients and local PKU Organizations nationwide. To learn more about the NPKUA, visit their website, www.npkua.org.

We are a registered 501 3c Non-Profit. For more information or to donate, please call or visit our website.



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PKU Organization of Illinois

Serving the PKU and Allied Disorders Community

About the Organization

The PKU Organization of Illinois was formed in 1969 by parents and medical staff from the PKU community hoping to be a resource to other families with PKU. This is still the case today. In addition to PKU families, we support teens, adults and those who have left diet who hope to return. In addition to PKU, we support 16 Allied Disorders.

The board of directors is comprised of 11 voting positions and 3 non-voting positions. We have 10 committees open to inquiring members. If you are interested in joining the board, email us at PKUillinois@gmail.com. Voting to become a member occurs annually at our Annual Meeting.

Events

Each year we try to host a variety of events that cater to different lifestyles and demographics. Check out our website and PKU Press for further information.

- Family Fund Day - NPKUA walk
- New Parent Coffee
- Cooking Classes
- Family Camp
- Wine Tasting & Silent Auction
- Scholarships
- Annual Education Meeting



Communication

PKU Press –Newsletter distributed two times per a year and mailed or emailed per your request. The PKU Press includes Information on events, highlighted PKU and AHD kids in the community, recipes, clinic updates and much more!

Electronic Invites –We send emails one to two times a month letting you know of upcoming events, activities, and information. The emails include registration links to each event and activity. If there is a fee for an event you can pay ahead using PayPal. You always have the option to mail in your registration with a check or money order.

Website– Visit us online for the most up-to-date information: www.pkuil.org



Our Mission

The PKU Organization of Illinois focuses efforts in three main areas: education, support, and research.

PKU families need to understand the importance of sticking to the diet, to cope with issues that the diet raises, and to never feel alone when trying to meet this challenge. We help with these issues in a variety of ways.

The PKU Press and our website are forums for the exchange of new information, ideas, recipes, and encouragement. Our annual "Family Camp", new parent coffees, social events, educational forums, and cooking classes aim to bring families together for friendship, learning, and support. Our annual meeting has captured national attention for the quality of its presentations on PKU research and treatment from prominent researchers in the field. Our legislative committee works with lawmakers to protect the interests of PKU families. Our annual scholarship is awarded to students, with PKU and AHD, that plan on or currently attend a college, university or vocational school.

The PKU Organization of Illinois remains committed to supporting research aimed at better understanding PKU and eventually finding a cure. Research initiatives we've supported include the Maternal PKU Project, gene therapy and clinical trials of the PKU drug tetrahydrobiopterin (Kuvan). We are always on the lookout for promising research that needs funding.

