



Web-Links



PKU and Allied Health Disorder Websites

www.pkuil.org

The Illinois PKU website includes links to diet/management, local resources, legislation, a listing of social events and fundraisers, and links to external sites including the Children's PKU Network, the National Society for PKU, and "A Place of Our Own" – a site for adolescents, teens, and young adults with PKU.

www.pafoundation.com

The Propionic Acidemia Foundation website includes information on research, family stories, events, and a chat room.

www.oaanews.org

The Organic Acidemia Association website includes information on the allied metabolic disorders, newborn screening, and links to multiple resources.

www.msud-support.org

The MSUD Family Support Group website includes information about the condition, archives to newsletters, events and resources, and a link to support groups.

www.pkunews.org

The National PKU News website provides information and resources on legislation and policy, diet, personal stories, scholarships, research, and information for adults with PKU.

www.npkua.org

This website provides current information on the development of the National PKU Alliance. The NPKUA is working to unify the PKU community by forming a national non-profit organization to support individuals, families and loved one affected by PKU. Visit this website for information on Board members, meeting minutes, news and how to become involved.

<http://www.pahdb.mcgill.ca/?Topic=Information&Section=Clinical&Page=1>

The Montreal Children's Hospital's PKU Resource Booklet for Families.

www.pku.com

A website created by BioMarin that provides information about living with PKU and includes a forum for individuals to post questions and responses.

www.patientpower.info/specialeditionpkufall.asp

Patient Power is a website that features radio programs on a variety of medical conditions, including a special edition series, "Living Better with PKU." Experts in the field are interviewed as well as patients to provide different perspectives on the topic of discussion. The transcripts from these broadcasts are available on this website.

www.myPKUtoolkit.com

A website created by Applied Nutrition Corp. and Children's Hospital Boston. Diet tips and model forms for self-management and advocacy can be downloaded.

www.ygyh.org

The Your Genes Your Health webpage focuses on several genetic conditions (including PKU) with explanations and illustrations of the genetics of the condition, incidence, inheritance, symptoms, testing/screening, living with the condition, and treatment.

<http://www.citt.ufl.edu/team/PKU/beta/index.html>

This website was developed by staff members from the Division of Genetics at the University of Florida to teach children about PKU management through interactive games and stories. A section for parents is available as well.

Services for Families Websites

www.thecenterweb.org/starnet/index.html

Illinois Star Net is a group that provides assistance to families who have young children with special needs. In the Resources section there is a link for funding opportunities to help families with financial assistance when attending seminars or conferences.

www.internet.dsc.uic.edu/dscroot/parents/transition.asp

The Division of Specialized Care for Children (DSCC) website on transitions that includes links and resources that are geared to both the parents and the child.

www.thearcofil.org

The Arc of Illinois is a group devoted to advocating for individuals with special needs. This website includes information on how to apply for waivers as well as information about upcoming events and seminars.

www.wrightslaw.com

This website is devoted to providing information about education law and how to advocate for individuals with disabilities.

General Genetics/Newborn Screening Websites

www.idph.state.il.us

The Illinois Department of Public Health is responsible for protecting individuals through the prevention and control of disease and injury. Health programs, including Division of Health Assessment and Screening/Genetics Newborn Screening Program are among the comprehensive services and programs that are available through IDPH.

www.newbornscreening.info/Parents/aminoaciddisorders/PKU.html

A comprehensive resource on genetic disorders for parents and professionals.

www.marchofdimes.com [www.marchofdimesillinois.org]

Website provides information on this group's overall mission of treatment and prevention of birth defects through programs of public and professional education as well as research. General health library included fact sheets on newborn screening, genetic conditions, as well as general health-related information on pregnancy and prevention of birth defects. Sites include information on funding for research and community service grants, volunteer development and training.

www.raredisorders.org

The National Organization for Rare Disorders offers patient support programs and information for genetic conditions. One specific program includes PKU and the costs associated with Kuvan for individuals that meet eligibility requirements.