

Really Living with PKU

Information for parents of newborns with PKU

The video, 'Really Living with PKU' was created to give families with newly diagnosed infants the reassurance that, with proper medical and nutritional care, their newborn will lead a normal life. The video shows infants, children, adolescents, and their families adapting to PKU, discussing the changes PKU has made for their families, and promoting day-to-day activities and long-term treatment.

Phenylketonuria (*PKU*) is an inherited disorder in which the body is not able to utilize the amino acid phenylalanine. High blood phenylalanine levels can cause permanent brain damage in individuals with PKU. Children with PKU who are identified as newborns, started on treatment, and have low blood levels are saved from this damage. The only effective treatment for PKU is a diet limited in phenylalanine. A special formula is necessary to maintain good blood levels and good health. Children with PKU have their full potential for intellectual and physical development.

Your PKU Clinic will provide the details of diagnosis and treatment. We hope that seeing families and children who are 'really living with PKU' will help families understand that PKU is an important part of family life and that maintaining family life is an important part of PKU treatment. Learning about and managing the PKU diet takes some time, but with a positive attitude, kids and families learn problem solving skills and creative approaches that become assets in other aspects of their lives.

You will find that children with PKU are responsible, intelligent, empathic, and will develop strong problem-solving skills. We think that children with PKU are extraordinary in many ways. We hope that this video inspires families to 'really live with PKU'.

This video presentation was produced by PKU Action Group along with the University of Washington Phenylketonuria Biochemical Genetics Clinic, and Richard Montequé of Meadowlake Productions. Several families of the PKU Clinic were ready and eager participants and we thank them all for their enthusiasm. We are especially grateful to the Neill family, the Don Welch Memorial Fund, Mrs. Vernita Thompson, and Dietary Specialties for their generous underwriting support.



The PKU Action Group (PAG) is a nonprofit volunteer organization whose mission is to act as an advisory resource group to the PKU Clinic, children, adults, and their families who live with PKU. The PAG is exempt from federal income tax under Section 501(c)(3) of the Internal Revenue Code. Information about the PAG can be found at <http://depts.washington.edu/pku/>, by emailing pku@u.washington.edu, or by writing the PKU Action Group, PKU Clinic, CHDD, Box 357920, University of Washington, Seattle, WA. 98195.



For additional copies of this video, please contact the Children's PKU Network, 3790 Via De La Valle, Suite 120, Del Mar, CA. 92014.
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