



The PKU Action Group, in cooperation with the University of Washington 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 organization and is exempt from Federal Income Tax under Section 501(c)3 of the Internal Revenue Code.

The PKU Action Group 2007 Annual Report

About Us

The PKU Action Group was founded in 2000 by parents of children with phenylketonuria (PKU) and by professionals in the field of metabolic disorders. Since then it has been our goal to create and maintain high quality educational and support programs for the benefit of the PKU community and in that time we are proud to have established a variety of programs and services that support Washington State families and individuals living with PKU.

Our Programs

Starter Kits are free to parents of newborn PKU babies. Valued at \$300, each Starter Kit includes a low protein cookbook, a gram scale, a food list that contains 185 pages of essential nutritional data for thousands of food choices, a binder full of important insurance and medical data, and more. In 2007, five families received Starter Kits.

Scholarships are awarded to Washington State high school graduates with PKU who are continuing their education at four-year or two-year colleges or at vocational institutions. In 2007 three awards were given, totaling \$2,240. Since the PKU scholarship program was established four years ago, a total of \$5,000 has been granted.

Education about PKU and treatment continues to be an important objective for the PKU Action Group. This year one hundred DVDs of the Group's *Really Living with PKU* were distributed nationally. Copies of *Maternal PKU: Choices You Can Live With* are also available upon request. Both videos can be streamed from our website.

In association with the Biomedical Genetics Clinic of the University of Washington and the Washington State Newborn Screening Program, another *Science Night* program was held for parents and adults. The format of *Science Night* allows families and individuals to meet in a casual environment and provides a non-clinical educational opportunity to learn more about PKU. Through a video link to Spokane, families on both sides of the state can participate in this informative and well received annual event. This year's topics included Updates on Expanded Newborn Screening, Milestones in the Treatment of PKU, and Measuring the Potential of New Treatments for PKU.

Camp Sealth, a Camp Fire Camp located on Vashon Island, provides a wide variety of overnight programs including specialty camps for children with special needs such as diabetes and PKU. The PKU Action Group provided three scholarships for children to attend during PKU Week in July. A grant from Mead Johnson Nutritionals provided funds for onsite nutritional support staff.

Special Outreach and community support efforts include:

- Emergency funds to provide low protein foods for pregnant women or families in need.
- Parent-to-parent contact as requested through our Family Mentor Program.

- Gifts of low protein cookbooks to those who cannot afford them.
- An Internet listserv to provide members with information about topics and events.
- Frequently Asked Questions (FAQs) and answers posted on the Group's website.

Two New Programs were and added to our outreach programs in 2007. The first entails sending a birthday wish to children celebrating their first birthday, along with a box of low protein cake mix. The second is to provide a free lancet device used for blood tests, to anyone with PKU in the state who needs such a device. LifeScan, Inc. and Haggen/Top Food and Drugs were the generous in-kind donors for this program.

Fundraising and Finances

In addition to the contributions made by our generous donors, our second Wine Tasting and Silent Auction was held in February and raised over \$4,000. Another very successful bike ride conducted by board member Cris Trahms, using *Ride Around Puget Sound* as a focus, netted over \$7,000 for the PKU Action Group Scholarship Fund. Our dedicated board of directors, Dorothy Corry, Andrew Iseminger, Jon Elliot, Holly Watkins, Martha Radabaugh, Erika Klimecky, Cris Trahms, Janet Garretson, and Marta McClintock continued to build on our strong financial foundation and provide leadership excellence.

Thank You!

PKU is a rare metabolic disorder. New families must deal with a great number of changes and are often overwhelmed by the requirements of the dietary management required for optimum health. People living with PKU face many challenges in day-to-day life that require the development of important lifelong skills.

The programs and services provided by the PKU Action Group are designed to directly support families and individuals at all age levels and to guide them toward positive solutions to changing and often difficult situations. While we are proud of the work we have accomplished, we are even more excited about our future.

In 2007 we continued our programs in support of the 250 families living with PKU who are followed by the University of Washington PKU Clinic. We could not have done so without our friends and contributors, whose support is critical to our work. Your consideration is greatly appreciated.

Please accept this invitation to join us in our continued work to provide these services and programs to the PKU community and to help create new programs that will meet the needs of families and individuals in Washington living with PKU.

To all our friends, thank you again for your kind and generous support.