

PKU RESOURCES

National PKU Alliance – www.npkua.org 1-877-NPKUA-22

The National PKU Alliance works to improve the lives of individuals and families associated with PKU through research, support, education and advocacy, while ultimately seeking a cure. The NPKUA is the first national non-profit organization to unite adults, families, statewide organizations, the medical community and PKU-friendly businesses under one umbrella organization.

NORD (National Organization for Rare Diseases) — www.rarediseases.org; 1-800-999-6673

NORD is a not-for-profit health agency dedicated to the identification, treatment, and cure of rare “orphan diseases” such as PKU through education, advocacy, research, and patient services programs. NORD helps eligible patients – those with medical and financial needs – afford the medications and treatment their healthcare professionals have prescribed.

Patient Power – www.patientpower.info 1-877-232-5445

Patient Power® is a series of online radio and video programs for patients hosted by Andrew Schorr, a 13-year Leukemia survivor and patient advocate. The programs feature renowned medical experts and inspiring patients discussing an array of chronic medical conditions including PKU. The end goal is patient empowerment.

PKU Listserv - Listserv@Listserve.Emory.Edu

The PKU Listserv is a great place for families of a child with PKU, persons with PKU, and professionals involved in PKU treatment to share their ideas and concerns with others. This list provides an easy way for people all over the world to come together and communicate with one another about PKU. If you are interested in joining the listserv, send an email request including your name and email address to: macpku@verizon.net.

PKU News – www.pkunews.org (206) 525-8140

National PKU News is a non-profit organization located in Seattle, Washington dedicated to providing up-to-date, accurate news and information to families and professionals dealing with PKU. Since 1989, it has provided a 16-page newsletter three times yearly, and also has available widely used resources for PKU families including a food list, 2 cookbooks, and a children’s book.

PKU.com – www.pku.com

PKU.com provides comprehensive information about PKU and a place to meet others with PKU. Log on today to join the discussion and to make new PKU friends. Join at www.pku.com.

PKU FORMULA & FOOD COMPANIES

Abbott Nutrition

– http://abbottnutrition.com; 1-800-227-5767

Abbott Nutrition has provided medical nutritional products for the management of PKU since 1987. These products include Phenex-1 for infants and toddlers, and Phenex-2 for children and adults. Speak to your healthcare professional to request materials, including family guides, food lists, and product trial kits.

Applied Nutrition

— www.medicalfood.com; 1-800-605-0410

Applied Nutrition is a leading PKU formula company that offers more options for more people. They make the PhenylAde brand of PKU formula which tastes great and is easy to use. Get back on diet by sampling the progress made in PKU formula. You can taste the difference with PhenylAde!

Cambrooke Foods — www.cambrookefoods.com

1-866 4 LOW PRO

Cambrooke Foods offers a complete line of nutritional, convenient, exceptional tasting food and formula for people with metabolic disorders, such as PKU. Cambrooke has evolved into not only a major supplier of low protein foods for people on restricted protein diets but now offers Camino pro™ an exciting line of food friendly metabolic formulas.

Dietary Specialties – www.dietspec.com

1-888-640-2800

Dietary Specialties has been providing low protein meal solutions to the PKU community for many years. From old favorites like macaroni & cheese and pizza to our new microwavable meals, we have everything you need to maintain your diet.

Ener-G Foods – www.ener-g.com

1-800-331-5222

Ener-G Foods has produced food for people on medically restricted diets since 1962. All of our products are wheat-free, gluten-free, dairy-free, nut-free and kosher certified. We also produce items for low protein diets.

Mead Johnson Nutrition

– www.mjn.com; (812) 429-5000

Mead Johnson is a global company with more than 70 products in over 50 countries. Mead Johnson is known for their Enfamil® and Enfalac® families of infant formulas as well as for products for inborn errors of metabolism, such as PKU. Mead Johnson is committed to creating nutritional brands and products trusted to give infants and children the best start in life.

Med-Diet – www.med-diet.com

1-800-MED-DIET

Med-diet is a company dedicated to making a difference in the lives of people who have medical conditions, such as PKU, that require a major change in their diets by providing high quality, good tasting and convenient food.

Nutricia/SHS North America

– www.myspecialdiet.com; 1-800-365-7354

Nutricia North America is a world leader in advanced metabolic nutrition. We have a great range of medical foods, formulas, and low protein foods for low protein diets. Recently, we added animal pasta, rice, and cake mix to our product offerings.

PKU Perspectives

– www.pkuperspectives.com; 1-866-PKU-FOOD

PKU Perspectives offers a unique and economical collection of over 200 yummy food products for maintaining a low protein diet. With no minimum order size and FREE shipping in the Continental USA, let us help you “Bloom where you are planted...”

Taste Connections

– www.tasteconnections.com; (310) 371-8861

Taste Connections was formed in 2003 by a mother to a child with Homocystinuria, a metabolic disease that requires a special diet similar to PKU. Taste Connection specializes in low-protein products and formulating quick and easy recipes, inspiring metabolic patients to stay on their life-saving diet.

VitaFlo – www.VitaFloUSA.com

1-888-VITAFLO

VitaFlo USA is pleased to provide a comprehensive range of convenient and flexible products for PKU. The ready to drink cooler system with DHA is perfect for people on the go, and is available in three different pack sizes. Additionally, PKU gel and PKU express powder are also great solutions for individuals looking to simplify their diets and improve their quality of life.

PHARMACEUTICAL COMPANIES

BioMarin – www.bmrn.com; 1-866-906-6100

BioMarin develops and commercializes innovative biopharmaceuticals for serious diseases and medical conditions. BioMarin has brought three medicines to market in 10 years, a testament to its dedication to patients with serious unmet medical needs. One medicine in particular, KUVAN® is approved to reduce blood Phe levels in patients with hyperphenylalaninemia (HPA) due to tetrahydrobiopterin- (BH4-) responsive PKU. KUVAN is to be used in conjunction with a Phe-restricted diet. Call BPPS: 1-877-MY-KUVAN (1-877-695-8826), or email bpps@bmrn.com to find out about Kuvan’s free 30-day trial.

OTHER TREATMENT OPTIONS

LNAAs

Large neutral amino acids (LNAAs) are used as treatment options for those with PKU. High levels of phenylalanine (phe) inhibit transport of amino acids in patients with PKU. Direct effects of elevated brain phe and depleted LNAAs are major causes for disturbed brain development and function in PKU. Supplementation with Large Neutral Amino Acids blocks uptake of phe, therefore reducing phe in the brain and in turn increases the uptake of amino acids needed by the brain to function properly and effectively. The companies below provide LNAAs formulas for patients with PKU by clinic authorization:

Nutricia – Lanaflex

www.shsna.com; 1-800-365-7354

Applied Nutrition – PheBloc

www.medicalfood.com; 1-800-605-0410

Solace Nutrition – Prekunil and Neophe

www.solacenutrition.com;
1-888-8-SOLACE

LOCAL PKU ORGANIZATIONS

NATIONAL PKU ALLIANCE PARTNER ORGANIZATIONS*

ARIZONA

Arizona PKU — www.arizonapku.org
Contact: Mark Stanley,
mstanley@deliveryfinancial.com

CALIFORNIA

Children 's PKU Network — www.pkunetwork.org
3790 Via de la Valle # 120 Del Mar, CA 92014
Contact: Rhonda Connolly, pkunetwork@aol.com

CONNECTICUT

New England Connection for PKU and Allied Disorders (NECPAD) — www.necpad.org
P.O. Box 3235 Woburn, MA 01888-2135
Contact: Rachel Kaup, fuzzyornge@hotmail.com

DELAWARE

The Mid-Atlantic Connection for PKU and Allied Disorders (MACPAD) — www.macpad.org
P.O. Box 6086 Lancaster, PA 17607-6086
Contact: Judy Griffith, judygriffith333@comcast.net

FLORIDA

Florida PKU Foundation — www.floridapku.org
Contact: David Donatucci,
david.donatucci@gmail.com

GEORGIA

Georgia PKU Connect — www.GeorgiaPKU.org
3300 Hamilton Mill Road #102-120 Buford, GA 30519
Contact: Kristen Vanags, Jennifer Anderson Lee,
and Julie Cheek, info@georgiapku.org

IDAHO

Intermountain PKU and Allied Disorders Association
P.O. Box 9762 Salt Lake City, UT 84109
Contact: Amy Oliver, ipkuada@yahoo.com

ILLINOIS

PKU Organization of Illinois — www.pkuil.org
P.O. Box 102 Palatine, IL 60078
Contact: Julie Kelly, juliepku@comcast.net

INDIANA

Indiana PKU and Allied Disorders Association
www.indianapku.org
P.O. Box 28 Carmel, IN 46082
Contact: Michael Franklin,
franklin_michael_t@lilly.com

IOWA

Iowa PKU Foundation
www.iowapkufoundation.com
P.O. Box 220 Des Moines, IA 50301-0220
Contact: Blythe Stanfel, bstanfel@gmail.com

MARYLAND

Maryland Alliance of PKU Families
<http://mapkuf.blogspot.com>
2028 Conan Doyle Way, Eldersburg, MD 21784
Contact: Rob Kerr, rkerr1699@gmail.com

The Mid-Atlantic Connection for PKU and Allied Disorders (MACPAD) — www.macpad.org
P.O. Box 6086 Lancaster, PA 17607-6086
Contact: Sharon Johnstone, info@macpad.org

MAINE

New England Connection for PKU and Allied Disorders (NECPAD) — www.necpad.org
P.O. Box 3235 Woburn, MA 01888-2135
Contact: Rachel Kaup, fuzzyornge@hotmail.com

MASSACHUSETTS

New England Connection for PKU and Allied Disorders (NECPAD) — www.necpad.org
P.O. Box 3235 Woburn, MA 01888-2135
Contact: Rachel Kaup, fuzzyornge@hotmail.com

MICHIGAN

Michigan PKU and Associated Disorders
www.michigan-pku.org
3062 E. Lois Midland, MI 48640
Contact: Sandy LaPrad, smlaprad@yahoo.com

MINNESOTA

Minnesota PKU Foundation — www.mnpku.org
A Place of Our Own
1397 Arden Oaks Drive Saint Paul, MN 55112
Contact: Tanya Drake, Tanya.d@comcast.net

MISSOURI

Missouri PKU Group
Contact: Patty Van Norman, rjcmom@att.net

NEVADA

Intermountain PKU and Allied Disorders Association
P.O. Box 9762 Salt Lake City, UT 84109
Contact: Amy Oliver, ipkuada@yahoo.com

NEW HAMPSHIRE

New England Connection for PKU and Allied Disorders (NECPAD) — www.necpad.org
P.O. Box 3235 Woburn, MA 01888-2135
Contact: Rachel Kaup, fuzzyornge@hotmail.com

NEW JERSEY

The Mid-Atlantic Connection for PKU and Allied Disorders (MACPAD) — www.macpad.org
P.O. Box 6086 Lancaster, PA 17607-6086
Contact: Sharon Johnstone, info@macpad.org

NEW YORK

The Mid-Atlantic Connection for PKU and Allied Disorders (MACPAD) — www.macpad.org
P.O. Box 6086 Lancaster, PA 17607-6086
Contact: Sharon Johnstone, info@macpad.org

OHIO

The Mid-Atlantic Connection for PKU and Allied Disorders (MACPAD) — www.macpad.org
P.O. Box 6086 Lancaster, PA 17607-6086
Contact: Sharon Johnstone, info@macpad.org

PENNSYLVANIA

The Mid-Atlantic Connection for PKU and Allied Disorders (MACPAD) — www.macpad.org
P.O. Box 6086 Lancaster, PA 17607-6086
Contact: Sharon Johnstone, info@macpad.org

RHODE ISLAND

New England Connection for PKU and Allied Disorders (NECPAD) — www.necpad.org
P.O. Box 3235 Woburn, MA 01888-2135
Contact: Rachel Kaup, fuzzyornge@hotmail.com

TENNESSEE

Tennessee PKU Foundation
www.tennesseepku.org
5468 Sabin Court Murfreesboro, TN 37128
Contact: Kellye McDowell, kellye@tennesseepku.org

TEXAS

North Texas PKU Association — www.ntxpku.org
325 S. Juniper Road #838 Allen, TX 75002
Contact: Kelly McDonald, kellymcdonald6@gmail.com

UTAH

Intermountain PKU and Allied Disorders Association
P.O. Box 9762 Salt Lake City, UT 84109
Contact: Amy Oliver, ipkuada@yahoo.com

VERMONT

New England Connection for PKU and Allied Disorders (NECPAD) — www.necpad.org
P.O. Box 3235 Woburn, MA 01888-2135
Contact: Rachel Kaup, fuzzyornge@hotmail.com

VIRGINIA

Ryans PKU Foundation
www.ryanspkufoundation.org
2127 Kingsley Lane Chesapeake, VA 23323
Contact: Mike Foust, mike_oanh@verizon.net

PKU Pursuits, Inc.

www.pkupursuits.org
PO Box 6739, Falls Church, VA 22040
Contact: Hollon Stevens, pkupursuits@gmail.com

WYOMING

WyoMed Campaign Organization
www.wyomedcampaign.org
P.O. Box 343 Meeteetse, WY 82433
Contact: Kenneth Allen, kennethallen@presidency.com

OTHER PKU ORGANIZATIONS

NEW YORK

Inherited Metabolic Disorders Support Group of Suffolk County
80 Picket Lane Centereach, NY 11720-2511
Contact: Ann Marie DiGeorgio, pkubegone@optonline.net

OKLAHOMA

Oklahoma PKU Support Group
35860 Cherry Hill Road Asher, OK 74826
Contact: Theresa Beverage, gtjbev@msn.com

OREGON

Oregon PKU Support Group
Contact: Jennifer Jones, jltjones@hotmail.com

WISCONSIN

PKU and Allied Disorders of Wisconsin
www.padow.org
6285 Schumacher Road Waunakee, WI 53597
Contact: Stephanie Stremer, ssstrem@uwhealth.org