

COMING SOON!!!!

OUR FIRST "WALK" FOR PKU RESEARCH- May 4
And
CONFERENCE 2002 "Diet For Life"- August 2



**A Message From the
MACPAD President**

This year MACPAD has some exciting activities and opportunities for you to meet and make friends with other families dealing with PKU and other metabolic disorders. Join us for our first walk-a-thon in New Jersey on Saturday May 4, 2002 or for our conference and picnic on August 2nd and 3rd. Both of these events will provide opportunities for learning about the low protein diet, meeting other families and having fun. You can also meet others by attending one of our support groups. If you have any ideas or suggestions or want to help, please let us know. The success of our group depends on the involvement of its members! So, now is the time to join in and have fun!



**New Feature for MACPAD
Website**

We are gathering a list of local stores that carry low protein specialty products or regular products for the PKU diet that are hard to find. You can see this list at www.pkumac.org. Send us the names of local stores that either carry low protein specialty products or regular products for the PKU diet which are hard to find. We will add them to the list of stores below by location! Email Laura@pkumac.org now! Or call 717-872-7546.

NOTE: We recommend that you call the store prior to making a trip to ensure that the product is in stock. We also recommend that you check all products that do not appear in the low protein food list with your dietitian. For example, many of the stores carry gluten-free products that are not always low in phenylalanine.



PICNIC 2002- August 3!

Please mark your calendars now for the 15th Annual MACPAD Picnic. It will be held Saturday, August 3, 2002 at the Weaver's Farm. It will be the day after our Conference, so hopefully we'll see everyone who attends the Conference on the 2nd. We plan to have food, games, and good times. More information will be in the next newsletter and we'll do a separate mailing. Anyone wishing to assist with games, etc.,

please email Carol Barton • cabbi@dejazzd.com. We are looking for donations for door prizes also, so please don't hesitate to let me know! Thanks. Carol Barton, Picnic Co-Chairman



The Cambrooke Foods family is pleased to announce the addition of Home Style White Sliced Bread and Macaroni and Cheese to our growing line of low protein foods.

Originally inspired by our two children with classical PKU and the countless hours dedicated to their low-protein diet, we created Cambrooke Foods to offer wholesome and delicious new alternatives. With the help of food scientists and technologists Cambrooke Foods has been developing low-protein food products since 1992. We have developed a unique product line that compares to its high-protein equivalents. We turned our passion for feeding our children to helping others whose medical conditions require a low-protein diet.

Currently available are a variety of bagels, breakfast bars, artisan bread, sliced and shredded cheeses, chocolate covered raisins, chocolate bars, wheat starch, pastas including rice, orzo, elbow macaroni, and couscous.

We recognize your desire to purchase products in smaller quantities and now feature several variety packs!

Try Cameron's Variety Pack, which features favorites like Artisan bread, plain bagels, American cheese, French toast energy bars and new orzo (a tender oval-shaped pasta, great for mixing with vegetables or serving plain with

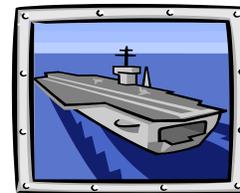
butter). The cheese variety pack includes a sample pack of American, Swiss and Jalapeño cheese. The Jalapeño cheese is great for the Mexican dishes that are popular with the kids. The bagel sample pack features a selection of our bagels and mixed fruit energy bars.

Information is available on our website for the "Green Light" direct billing service. This program is for customers whose insurance providers have given prior approval for Cambrooke Foods to bill them directly for their food purchases.

Help a friend in need of low protein foods or celebrate an occasion with a gift of a Cambrooke Foods Gift Certificate -- good for any delicious Cambrooke Foods purchase. Check out our website regularly for new products and join our mailing list (easily done by e-mailing us or calling us) so you will be advised of special offers.

Cambrooke Foods has been busy over the last few months not only working on bringing more delicious low-protein foods to your table, but improving customer service, shipping policies and payment options.

Our new Customer Service Manager and our friendly staff are working to make the ordering process easier. You can order 24/7 through our call center, toll-free at (866) 4 LOW PRO or easily over our website at www.cambrookefoods.com. If this is not convenient for you, you can mail or fax your orders to us.



If anyone is still interested in the PKU Cruise on July 18-22, 2002 from New York to Nova Scotia Canada on Carnival Cruise Lines, please let me know. This is the last call for the cruise!

Pat Byrne, Cruise Consultant
 Mom to Krista, 13 CPKU
patb@wingsgt.com or 610-277-6850



**Happy Birthday
 To Our MACPAD Friends!**

Michael Chirigos	Feb. 19
Greg Orris	Feb 20
Stephen Bodden	Feb. 8
Heather Matthews	Jan. 16
Dennis Blouch	Jan. 31
Madison Hostetler	Feb. 9
Patrick Heath-Bowman	Feb. 15
Cortney Unger	Feb. 1
Jacob Graver	Feb. 25
Abigail Myers	March 9
Daniel Gilbert	Feb. 28
Greg Reynolds	Jan. 27
Rebecca Lehman	Mar. 12
Amanda Bracero	Mar. 5
Robert Schreck	Mar. 2
Sherif M. Ismail	Mar. 9

Join Us For



A Walk in the Park to Support PKU Research!

Put on your walking shoes and some comfortable clothes and join us for a fun filled early spring day at the park! On May 4th, 2002, MACPAD will hold its first ever walk in the park to support PKU Research.

WHEN: Saturday May 4,th 2002- Rain or Shine

TIME: 10:00 a.m. until 2 p.m.

PLACE: Washington Lake Park
626 Hurffville Cross Keys Road, Sewell NJ (one half hour from Philadelphia)
856-589-6427

WALK: Walk 1.5 miles or more (you choose the distance).
Each lap around the park is one and one half mile.

BENEFIT: All donations collected for the walk will be donated to MACPAD's research fund.

REGISTER: Please register by calling Deb Gilliano at 856-223-0307 or email
Info@pkumac.org
Let us know name, age, address, phone number and t-shirt size of all walkers!
Registration deadline- April 5, 2002

- Ⓢ Food, music, games, and lots of fun activities!
- Ⓢ Free t-shirts for everyone who walks (with at least \$25 in donations)!
- Ⓢ Prizes for the walking the most miles, collecting the most donations and more!
- Ⓢ Fruit, veggies and water for our walkers!
- Ⓢ Low protein cooking demonstration
- Ⓢ Bring a picnic lunch or buy your lunch at the park restaurant and food vendors (French fries and Italian Ice)!
- Ⓢ The park has playgrounds, basketball, skateboard, bike trails and beautiful scenery!

FOR DETAILS AND THE SPONSOR FORM, see the enclosed brochure ...



ENER-G FOODS, INC.

Our new Ener-G Low-Protein Baking Mix makes excellent bread in both Automatic Bread-makers and by traditional bread-pan methods. It also makes excellent pancakes. It is our item #4823 and sells for \$6.90 for a 5 lb package.

Ener-G Foods' Low Protein & Low Phenylalanine Pastas come in 5 delicious varieties.

#8150 Low Protein Lasagna	16 ounce package	\$5.49 / Case of 12 packages	\$ 59.29
#8152 Low Protein Macaroni	16 ounce package	\$5.49 / Case of 12 packages	\$ 59.29
#8153 Low Protein Small Shells	16 ounce package	\$5.49 / Case of 12 packages	\$ 59.29
#8154 Low Protein Spaghetti	16 ounce package	\$5.49 / Case of 28 packages	\$138.35
#8155 Low Protein Large Shells	16 ounce package	\$5.49 / Case of 12 packages	\$ 59.29

These pastas offer almost fool proof cooking. They don't fall apart, or get soggy or gooey, nor do they stick together as other pastas may, even if you overcook them a little.

The ingredients are: Corn starch, potato starch, and filtered water. Protein: 0.4 grams per 100 grams, Phe: 9 milligrams per 100 grams.

Ener-G Foods offers other ready-made Low Protein products as well: Cheese Crackers, Gourmet Crackers, Crisp Pretzels, Lemon Cookies, Rice Pizza Shells, Tapioca Bread, Cheddar Cheese, and Mozzarella Cheese.

Information on these items can be found on our web site at www.ener-g.com or by calling 800-331-5222.

Restricted diets don't have to be boring with Ener-G Foods, now in our 40th year.



Grandmas Corner

Dear

Grandma,

I am a grandmother of a child with PKU. She has a very small appetite and most days I have quite of bit of food leftover. What is the best way to store it for future use? Can we freeze leftover noodles? Also, my bread gets moldy very fast, how long is it good for in the freezer?

Answer: I too have a grandchild with a very tiny appetite and always have leftovers. At the price of the lo pro food, I had to find a way to keep it for future use. For Christmas, my husband bought me a vacuum sealer and that has been a huge success in our family. The nice part is that the bags you seal them in are also boilable, so you can freeze any leftover food in your vacuum seal package then take it straight from the freezer and drop it into a pot of boiling water to reheat. No messy pans and the food is just right. The bread is great with the vacuum seal and last much longer in the freezer than

regular freezer bags. I usually put 4 slices of bread in each package then vacuum seal it. No more freezer burn problems. It also works great with soups, spaghetti, noodles of any kind and I like to freeze individual slices of pizza. The crust on the pizza does not get so hard this way. The vacuum sealer is expensive, so if you don't have one or don't want to get one, just put the food in a zip loc bag and make sure you get as much air as possible out before you seal the bag.



New Labels for SHS metabolic formulas. SHS North America would like to announce changes to the metabolic labels for all Maxamaid and Maxamum formulas. Over the first few months in 2002, you will see improved graphics, label layout and mixing instructions. No changes have been made to the product. We also made minor changes to our Analog infant formulas and labels. For detailed information, please contact your dietitian or one of the SHS Nutrition Specialists.

New Loprofin labels. Loprofin packaging has a new face! SHS North America is in the final stages of changing the appearance of our Loprofin product range to a new, attractive packaging with easy to read nutrition information. No changes have been made to the products.

Recipe Contest. SHS North America invites **YOU** to take the challenge and enter your original Loprofin recipe into our 1st Annual Recipe Contest! Winner will receive a \$100.00 gift certificate towards our Loprofin Product range and your name and recipe will be posted on our website! Winning recipes will be selected on the basis of originality, presentation and overall appeal. All entries must use at least one product from the Loprofin product range. All entries must be original and previously unpublished low protein recipes. Deadline for all submissions is May 1, 2002. Entries must include the following:

Name Please fax, e-mail or mail your favorite recipe.

SHS North America
P.O. Box 117
Gaithersburg, MD 20884
E-mail: nutritionservices@shsna.com
Phone: 1-800-365-7354
Fax: 1-301-795-2301

Address/Phone Number
Name of recipe
Ingredients
Directions for mixing, baking/cooking, etc.

Editors note: This newsletter is meant to relay information about products and individual feelings. We do not attempt to replace advice from your physician or clinic on the treatment of metabolic disorders.

this same biscuit recipe by omitting the salt and dissolving a couple of teaspoons of sugar into the water to create a pancake batter.

Some cooks add 1/2-1 teaspoon methylcellulose per 1-cup wheat starch or baking mix to improve the texture. Best White Bread, another recipe on the MACPAD website uses this clever trick. Powdered egg replacer (not egg beaters) helps bind ingredients and improve the quality of recipes; in fact methylcellulose is an ingredient in egg replacer. Donna Taylor's cake recipe found on www.pku-allieddisorders.org makes an excellent birthday cake. Xanthan gum is used as a commercial stabilizer; it holds particles of food together making less crumbly breads. Adding 1 teaspoon of xanthan gum to 1-cup wheat starch or low protein baking mix is another way to improve the texture of baked items.

You can improve the taste of low protein breads by finding ways to add moisture after baking. Soak low protein bread in flavored non-dairy coffee creamer (found on page 84, Low Protein Food List); cinnamon-hazelnut is an excellent choice. Fry for an easy French toast. Make low protein stuffing using 2-3 slices low protein bread, a few tablespoons chopped celery and onions sautéed in margarine, 1/4-teaspoon poultry seasoning, and 2-3 Tablespoons Swanson vegetable broth. Heat thoroughly. Or grill the bread with your favorite low protein veggies and low protein cheese.

I have had a very positive response to the "Now We're Cookin'" video available from SHS North America. Diane Sullivan teaches step-by-step how to make low protein pizza, breadstick, dinner rolls, and English muffins. Even my toughest critics liked the recipes and found the visual instruction to be invaluable especially to learn the correct appearance of the dough.

Remember that your low protein foods do not last indefinitely. So, use them in a timely manner and check for the expiration date, which appears on some products.



New Packaging Available! Now, get a one-pound bag of low protein pretzels on sale until April 30, 2002!

One pound polybag of low protein pretzels only \$3.50 a bag (normally \$4.00!)

Order at www.unclehenry.com or 1-800-683-8375



Calling All Hands!

We invite everyone with PKU or an allied disorder to send your handprints to MACPAD. Our own quilter, Lynn Trump is creating a quilt, which will be given away at the annual picnic, this August 3. Your handprint must be on the quilt to make you eligible for the drawing. So, please, trace your handprint, include your name and date of birth and mail to MACPAD, P.O. Box 6086, Lancaster, PA. 17607! This quilt will not replace the raffle for the genuine Amish quilt!



The Dietary Shoppe, Inc.
(formerly The Dietary Specialties Shoppe, Inc.)

What's New Besides our Name??

George Washington Broth Packets
(Golden or Brown)
Med-Diet Cheese Sauce Mix
Loprofin Chocolate Cream Biscuits
Kame Bean Thread Noodles
Kogel Dessert Mix
(Orange, Grape, Raspberry)
Aproten Rigatoni Pasta
Loprofin Vanilla Cream Wafers
Stretch Island Fruit Leather
(Cherry, Grape, Strawberry, Raspberry)

Thank you for your continued support and suggestions!!

The Dietary Shoppe, Inc.
184A East Evergreen Avenue
Philadelphia, PA 19118
215-242-5302
<http://dietaryshoppe.com>

Pennsylvania Low Protein Modified Bill Legislation- HB1701

House Bill 1701, which adds low protein modified foods to the Medical Foods Insurance Coverage Act, is currently sitting in the Pennsylvania House Insurance Committee. If you would like to urge the Committee to approve the bill and move it to the House of Representatives for a vote, please send a letter to Representative Micozzie, who is the sponsor of the bill. Representative Micozzie's address is Representative Micozzie, Chairman of the House Insurance Committee, House of Representatives, 45 East Wing, House Box 202217, Harrisburg, PA 17120. If you would like a copy of a sample letter, you can request one from Judy Griffith at Info@pkumac.org or call 717-872-7546.

Lend A Hand, Make a Friend, And Learn Something New!

If you are interested or willing to do any of these things, please contact MACPAD about creating or joining one of our local Support Groups! Each support group makes up its own rules, plans its own activities and sets its own schedule.

The MACPAD South Central PA Support Group met for the second time at the end of January and had a morning filled with lots of conversation and candy making. We made the recipe for low protein Skor bars from SHS- and they were delicious. We also made some beautiful Valentines' Day candy for the kids. As part of our meeting, we shared some food that our children didn't eat and made some joint low protein purchases to share the shipping charges. Our next meeting is planned for Saturday April 19th; so if you are interested, please contact Judy Griffith at Info@pkumac.org or call 717-872-7546. If you are interested in joining or creating your own support group, let us know. We are in the process of putting together groups in northeastern PA and central NJ.



You can now order MACPAD items online at www.PKULife.com using a credit card!

We have made special arrangements for you to order **MACPAD T-Shirts** and our cookbook - **Creative Family Cooking - Recipes and Menu Planning for PKU** online. Just visit www.pkumac.org/OnlineStore.htm. This is a great, fast, easy way to order from MACPAD. Items ordered are usually shipped in 2-3 business days.

Creative Family Cooking - Recipes and Menu Planning for PKU is the newest cookbook for the PKU Community has sold over 600 copies to individuals in 42 states and 6 provinces of Canada! **MACPAD T-Shirts** are light gray with the MACPAD logo on the front. They are also machine washable 98% cotton and preshrunk.

Or, if you would like to pay by check or money order, you can still use the mail-in order form. Just complete the form on the website, print it and mail it to us with your check at MACPAD, P.O. Box 6086, Lancaster, Pa. 17607.

If there are other products that you would like to order online please Email Info@pkumac.org, or call 717-872-7546.

Conference 2002- Friday August 2, 2002



The MACPAD Board of Directors enjoying lunch at the conference site, The Lantern Lodge in Myerstown, PA. From left, Robert Johnstone, treasurer, Lynn Trump, board member, Karen Blackbird, honorary member, Carol Barton, board member, Sharon Johnstone, conference co chair and secretary, Laura Assayag conference co chair, Judy Griffith, President.

The conference committee has announced the preliminary schedule of events for our second conference. The theme of this year's conference will be "Diet For Life". We have arranged for special room rates at the Lantern Lodge in Myerstown, PA. You may call toll free 1-800-262-5564 to make your reservations. Tell them you are with MACPAD to get the special rate.

Babysitting will be available Free during the conference hours. This will be provided on a first come, first served basis, so please sign up for babysitting early. The following page is our registration form, which you may complete and return with your payment.

Preliminary schedule of events for Friday, August 2, 2002

9:00- ongoing **Vendors exhibits**

10:00 – 11:00 **Dr. Erik Puffenberger PhD.** will speak on "**Genetic Research in Isolated Populations**". Dr. Puffenberger is a research scientist at the Clinic for Special Children in Strasburg, PA and has worked in research since 1987. He will be discussing his research of metabolic diseases in the Amish and Mennonites of Eastern Pennsylvania.

11:00-11:15 break

11:15- 12:00 – **Small Group Discussions**

- A. **Sports/Social Events and PKU**- Ken Barton
- B. **Feeding a Toddler**- Laurie Graver
- C. **"Pocket Phe Book" Workshop**- Anne Starr

12:00- 12:45 Lunch

12:45- 1:45 "**A Family Lives With PKU**". **Christopher Prout** and his family will lead a discussion group on how metabolic disorders impact on each family member and how they have worked together to help Chris achieve. Chris is a 23 year old with PKU who has just graduated from Loyola College with a degree in Business administration and is now a financial representative with Northwestern Mutual Financial Network.

1:45-2:00 Break

2:00-3:00 **Fran Rohr, BS, MS** will discuss "**Adults on Diet: Factors for Success**". Fran is a clinical nutrition specialist at Children's Hospital in Boston and holds degrees from University of Maine and Tufts University. Fran has published several articles on metabolic disorders and is a well-known expert in the field.

3:00-5:00 Break. Time to visit vendors table and continue discussions with our speakers.

5:00- ? **Motivational Banquet** A spaghetti dinner will be served for everyone. Following the meal, **William Crosky** will be discussing "**Live Your Life**". Bill is the Vice President of the Western Region of City Digital in Irvine Texas and has PKU. He has been presenting motivational speeches since 1980 to groups such as Ross Laboratories National Sales Meeting, Akron Medical College and various PKU organizations.

“DIET FOR LIFE” CONFERENCE 2002 – REGISTRATION FORM

In order to plan we need some information about **all** the attendees. Please indicate on the following table each individual attending and which activities they plan on attending. This information will help us better plan to meet everyone's needs.

Planning to attend: Please check all that apply:												
Full Name	Adult or Child	Child's Age	Metabolic Disorder	Needs Baby-Sitting	Dr. Puffenberger	Group Discussions			Chris Prout	Fran Rohr	Friday Evening Banquet	Annual Picnic Saturday
					Genetic Research	Sports	Toddler	Pocket Phe Book	A Family Lives with PKU	Adults on Diet	William Crosky	Weaver Farm
1												
2												
3												
4												
5												
6												

Contact Information:

Street Address	City, State, Zip Code	Phone #	E-mail

Please return this form with the registration fee of \$35.00 per household plus \$5.00 per non-PKU person attending the banquet (people with PKU or allied disorder can attend the banquet free) to: MACPAD Conference 2002, P.O. Box 6086, Lancaster, PA 17607



Address: P.O. Box 6086
Lancaster PA 17607
Phone: 610-983-9369
Email: info@pkumac.org
Website: www.pkumac.org

Newsletter Contributors

Judy Griffith, Carol Barton, Sharon Johnstone, Laura Assayag, Debbie Gilliano, Kim Pepper, Linda Tonyes and Peg Lunt,

If you have information, or an article to contribute to the next Newsletter, please contact MACPAD. New contributors are WELCOME!

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