



### **“PKU WALK” Funds Benefit PKU Research**

2002 was a memorable year for MACPAD! Due to the success of our first annual “Walk” for PKU research we were able to provide funding to two worthy projects. The Clinic for Special Children, under the direction of Dr. Holmes Morton received \$24,200. We were also able to provide support, along with The PKU Organization of Illinois, to Dr. Barbara Burton at Children’s Memorial Hospital in Chicago. Following are updates on those projects.

#### **Research Update from Dr. Barbara Burton at Children’s Memorial Hospital in Chicago**

The study of Tetrahydrobiopterin (BH4) responsiveness in patients with PKU is progressing at a steady pace at Children’s Memorial Hospital in Chicago. A total of 21 subjects ranging in age from 6-32 years have been studied. These have included 18 patients with classical PKU and 3 with mild (or atypical ) PKU. None of the 18 classical PKU patients studied were found to be responsive to the BH4 administered. In other words, the BH4 did not result in any lowering of the blood phenylalanine level in these patients. Two of the 3 mild PKU patients tested for whom complete data are available were found to be BH4 responsive. Within 8 hours of receiving a single dose of BH4, one patient’s blood phenylalanine level dropped to within the normal range (1.2mg%). Additional classical and mild PKU patients are being recruited into the study. As additional data are being gathered from around the world, it is becoming clear that it is the mild PKU patients that are the most likely to be BH4 responsive. There is one documented example of a classical PKU patients who is BH4 responsive, however, so we feel that additional classical patients clearly need to be studied. Data on the specific mutations in the phenylalanine hydroxylase gene are being tabulated in all patients studied so that specific “responsive” mutations can be identified.

#### **Research Update From The Clinic For Special Children in Strasburg, PA**

Dr. Holmes Morton and staff are in the early stages of their metabolic research. They are beginning to identify appropriate subjects for the trials. They plan to study gene mutations of the phenylalanine hydroxylase gene that are biopterin responsive. Specific mutations of the gene produce an enzyme that can be activated by pharmacological doses of the cofactor biopterin. Dr. Morton has begun mutation analysis on his Amish and Mennonite families with PKU to determine the distribution and total number of mutations within these populations. Dr. Puffenberger, a molecular biologist, has sequenced the PAH gene in several patients and has found three different mutations in the gene. All three mutations are found in European populations and have been reported to be associated with relatively mild variants of PKU. One mutation that is found in both Amish and Mennonite population’s results in an amino acid substitution near the biopterin binding region of the enzyme and has recently been reported to be responsive to biopterin.

They will also be conducting biopterin loading studies and 12-month treatment trials to determine the effect of tetrahydrobiopterin upon amino acid tolerance and neurological signs. They plan to develop guidelines for the evaluation of mutations for biopterin sensitivity that can be applied to other populations.



## **Saturday, May 3, 2003...The Second Annual Walkathon for PKU Research**

We hope the New Year finds everyone healthy, happy and ready for our 2<sup>nd</sup> Annual Walk-a thon. The walk is being held on Saturday, May 3<sup>rd</sup> at Washington Lake Park in Washington Twp. NJ. Once again we have many fun and educational activities planned: cooking demonstrations, D.J. entertainment, magic shows, balloon art, craft and Tupperware sales, raffle tables and much more! We are in search of volunteers who would like to join us in making our walk a great time for all. We need individuals who would like to work at some of our tables, help with set-up and clean up or anyone who has a special talent for crafting that would like to make items to be raffled off. If anyone has any questions please contact **Janice @ (856) 478-0577 or Debbie @ (856) 223-0301. The money raised goes directly towards PKU research!**

---

We look forward to hearing from you and another successful Walk-a-thon Janice Paterno

---



Cambrooke Foods is fresh with new ideas and foods for 2003! Watch for our e-mail messages which will announce NEW Cambrooke products, or, take a moment and visit our web site for new recipes using our products to create more delicious meals for your family.

**Cambrooke's Rewards Club** will appeal to our regular monthly customers who are looking for convenience, a chance to give back to the Metabolic Community and rewards for their customer loyalty.

Here's how it works. Club members will have the opportunity to maintain a standard monthly order which can be altered during the course of the month as needed. Members will receive free samples of new products as they are introduced. At the end of a twelve-month period of continuous enrollment (with a one month "vacation break" if needed), they will receive 5% credit toward future food purchases (of their twelve month food total) and a check for the same 5% amount will be donated in their name to *PKU News* to support ongoing food product research. For Cambrooke's Rewards Club information, e-mail us at [CambrookeClub@Cambrookefoods.com](mailto:CambrookeClub@Cambrookefoods.com) or call us at: (866) 4 LOW PRO / (866) 456-9776 (option 6).

**A Recipe Challenge** for you this spring: Share with us an original great tasting recipe which uses three or more Cambrooke Foods products, with permission to be posted on Cambrooke's website. If we publish your recipe, you will receive a \$10.00 Cambrooke Foods gift certificate. If yours is selected as the best recipe entry based on taste, the number of products used and originality, you will receive a \$100.00 Cambrooke Foods Gift Certificate. Deadline for recipe entries is May 30, 2003. We will announce the winner in early June via e-mail.

**Rugelah** is back due to popular demand! These Eastern European specialties are small rolled pastries made from a very rich, low protein cream cheese and sweet butter dough. The delicate, flaky pastry encloses a raspberry filling. You will absolutely love this decadent dessert! Order while supplies last.

We are ALWAYS open to serve you. Call toll-free (866) 4 LOW PRO / (866) 456-9776 or visit our website at [www.cambrookefoods.com](http://www.cambrookefoods.com). If this is not convenient, you can mail, e-mail or fax your orders to us at [mykitchen@cambrookefoods.com](mailto:mykitchen@cambrookefoods.com) - (630) 839-7413 (fax), 2 Central Street, Framingham, MA 01701.



Colin Nicoli

## Colin's Story

My son, Colin, was diagnosed with Homocystinuria at 2 weeks after having the newborn screening test done when he was born. Homocystinuria is an inborn error of metabolism and there is a problem with the body's ability to break down protein. It is genetic and passed on from both parents who either have the disorder or are carriers of it. It is similar to PKU in that the treatment is somewhat the same, a protein restricted diet. But in PKU, phenylalanine is counted and in Homocystinuria, methionine is counted. I remember his pediatrician calling and saying that he needed to be seen right away at Children's Hospital and she went on about possible mental retardation. That was all I needed to hear. Of course I thought the worse.

I was stunned. I had no idea what we were in store for. I had never heard of this before and finding out that he got it from both of his parents didn't help. We had to go to the hospital every day for weeks to have blood taken. Thank God for the newborn screening and detecting this early. If gone undetected and untreated, mental retardation could happen and his lenses could become detached. Then we had to establish what was to be done about it. First he was given Pyridoxine (B-6). He didn't respond to that which meant that he had to be put on a protein restricted diet.... for the rest of his life including drinking a formula. The foods that he cannot have are meat (of any kind), dairy products, peanuts, and eggs. Basically anything high in protein.

There are many low protein food companies out there that have pasta and bread products. Cambrooke Foods, I have found, is the best for their quality of foods. He mostly eats the low protein pastas and vegetables (he loves his veggies thank God!) but he does get into the regular breads and the snack types of foods so that

makes it difficult sometimes. In the beginning, I he was allowed a certain amount of Methionine from food a day. Now we are trying something new. Now he's allowed 4-6 grams of protein a day.

In the beginning, I kept thinking why my child. Why does he have to have this wrong with him? To look at him you would never think he had anything wrong.

He is now 5 years old and in Kindergarten. It has been a hard and long struggle especially now where he is older. Finding a balance in what his levels should be has been tough as well. His levels have been up and down. His bloods levels are monitored for homocysteine and methionine levels. It is hard to deny your child food of all things but he knows what foods are "bad" and what foods are "good". He is a healthy, smart little boy and he is doing very well.

Talking to other people who have experienced this either themselves or their children is so helpful. It is very comforting knowing that other people understand what you are going thru and to bounce questions off of.

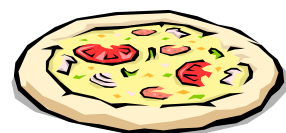
I am very lucky and grateful for Colin.

Thank you.  
Vicky Nicoli



## Saturday, March 29, 2003

Announcing a low protein bread and pizza-baking demonstration! Hershey Medical Center's dietitian, Karen Blackbird, is planning an exciting day in Lancaster County, PA Karen promises some delicious and easy to bake breads. Interested folks should contact Karen at 717-531-8006 to register and receive details about the demo.



## **Meet an Honorary Board Member**



**Karen Miller Blackbird, RD, MPA**

A PKU nutritionist for the Department of Pediatrics at The Milton S. Hershey Medical Center in Hershey, PA, Karen is an enthusiastic educator. She is responsible for the nutritional management of all children and adults with PKU enrolled in the Milton S. Hershey Medical Center PKU Clinic.

Karen graduated Magna cum Laude from Indiana University of Pennsylvania and completed a dietetic internship at Brigham and Women's Hospital in Boston. She graduated from Penn State University with a Master of Public Administration with emphasis in Health Care Management.

Karen is an honorary member of the Board of Directors of The Mid-Atlantic Connection for PKU and Allied Disorders and a member of the Central Pa Dietetic Association, Pennsylvania Dietetic Association and the American Dietetic Association. She has been chosen to lead various committees at the local level, most recently as chair for National Nutrition Month and Public Education for the Penna Dietetic Association Foundation.

She has been involved in clinical nutrition since 1981, holding positions as Senior Clinical Dietician and Manager, Department of Clinical Nutrition at the Milton S. Hershey Medical Center. Karen has been responsible for patients with varied medical conditions, both inpatient and outpatient. She continues to enjoy working with children and focusing on behavioral and physical issues influencing proper growth and development.

Karen and her husband home school their two children, Jordan (age 10) and Ethan (age 9) and enjoy golfing and involvement with their church's College Student ministry.

Karen is committed to "helping families help each other which is why she was so eager to see an active parent group developed for PKU and Allied Disorders. Karen has also quoted as being "eternally grateful that the planning and implementation of the annual PKU picnic is no longer on her shoulders".

---

## **Meet The MACPAD Secretary**



After a 33 year nursing career spanning Connecticut and Chester County, PA, my husband, Bob, and I decided to retire to Lancaster County, PA. I received my RN in 1963, and returned to school in the early 90's to obtain a BSN. I also have a certification as a Community Health nurse. Most of my career was spent in the geriatric field as a nursing supervisor or as a visiting nurse. My last position was as an adjunct-nursing instructor. I worked with students who were learning community health nursing by visiting the frail elderly in their homes.

My husband and I have two daughters, Laura and Judy. Laura has a daughter Kyla who is two. Judy has three boys, Charley, 5, and Bobby, 2, who have PKU and Nick, 7, who does not. My daughters and grandchildren are why I have become so active with PKU.

Laura and Judy founded MACPAD on May 8, 1998. The goal was to enrich the lives of those living with PKU and Allied Disorders by disseminating information, providing supportive activities and encouraging the exchange of ideas. It has been an exciting experience! I have worked on two conferences, edited our cookbook and am

currently the editor of this newsletter.

While I never expected to be so busy with MACPAD, Bob and I still find time to work in our greenhouse, play with our dog, Murray and enjoy a round of golf. I have recently taken up quilting and love the creative aspect of working on different patterns.

I have been blessed to meet some wonderful people through my involvement with MACPAD. I hope that, in some small way, I have been able to help fulfill the mission of MACPAD.

---

## Random Reflections



### Cooking with Kids

Cooking allows children to develop many skills. Their motor skills are honed by scrubbing, tearing, dipping, pouring, mixing, shaking, spreading, rolling, kneading, juicing, peeling, cutting, grating, and slicing (with supervision). Their language skills expand with naming things, comparing things, following directions, recognizing letters and words and their meaning and purpose. Social skills are developed by sharing, learning the concepts of teamwork, and self-care promoting cleanliness. Science skills are presented in a fun way such as concepts of hot and cold, floating, dissolving, evaporation, browning, melting, thickening, and a keen sense of smell.

With diet limitations, the challenge of cooking foods successfully raises the bar for self-esteem for the gourmet guru! Cooking and food preparation in the early childhood years can be time consuming and overwhelming. However, modeling healthy eating habits and good nutrition are actually very easy with a PKU diet. Fresh fruits and vegetables are easy to enjoy without a lot of creativity. The primary purpose in the activity of cooking together is time spent with each other! The essential point in quality parenting is realizing that the greatest gift your child can receive from you is YOU!

It might be fun to create a chef's hat using white construction paper rolled into a tube to fit their head, and tucking a handkerchief in the top to complete the look. They will not realize that they are learning. They will just think this is fun time together. The ability that will be

developed to follow directions is one of the most important skills that he or she will learn. The basic tools for the "rookie chef" would be a wooden spoon, plastic or metal mixing bowls, wire whisk, plastic nesting measuring cups, and a child sized apron, or oversized shirt of Dad's!

For parents that do not feel they are equipped to be teachers of cooking skills, I would suggest that your library or any bookstore provides many "learn to cook" books. There are also numerous Internet web sites, if your family has access to a computer. A site for fruit information is [www.dole5aday.com](http://www.dole5aday.com); and also a site that is very expansive is [www.vegweb.com](http://www.vegweb.com). You may find that you will enjoy the experience of learning to cook as much as your child!

It was very rewarding to watch our son in the early years be successful in mastering the preparation of his "special foods and treats". The toddler years quickly turned into teenage years, when he was able to be creative in our kitchen to satisfy his hunger before participating in an athletic event, to his creative ability in making soup and vegetable dishes in college.

Our PKU adult son, Joe, recently got engaged to Teresa Leerssen. She is a graduate of Furman University with an art education degree. She enrolled this September at Johnson and Wales Culinary School, in Charleston, South Carolina. It was a special blessing to have the TWO of them in our kitchen over the holiday.

Cindy Hoover

---

## Announcing our new web address!!!!

MACPAD can now be found on the web @

**WWW.MACPAD.ORG**

**Come visit us and see the changes!**







### For teens and young adults with PKU!

Do you have a question that can only be answered by someone who truly understands what it means to have PKU? Then, if you have a question for her, you can email [Info@MACPAD.ORG](mailto:Info@MACPAD.ORG), Attn: Jennifer or send your question to MACPAD, Attn: Jennifer, P.O. Box 6086, Lancaster, PA 17607. Names will not be used, if requested.

Dear Jennifer,

I am 24 years old and have PKU, along with my little brother. I read your story and was shocked to find that your story is almost identical to mine. I went off my diet some years ago and ever since then I have had no energy and am always tired and depressed. My husband and I have been married for 1 year and he can barely stand me with all the mood swings that I have. Until I read your story I had no idea that PKU was the main problem. I want to make my marriage a better one, but I don't want him to resent me. I want to be the girl I was in junior high when everyday was a great outlook and I wanted to wake up. I have tried before to go back on diet, but I could not keep the formula down. Please tell me how you did it. The formula is expensive and insurance doesn't cover PKU and they never will. Please tell me your secret. How do you do it? I am begging for your help. I want to live long and stay healthy and better yet, live my life happy. Thank you so much. I look forward to hearing from you.

Answer:

The key to being successful on diet is determination and perseverance. Once you make upon your mind that you truly want to do it, you have to take it one day at a time. It is hard sometimes but you have to keep going and don't ever give up. You will have good days and bad days. Don't beat yourself up if you make a mistake. You're human!

You also have to get as much support as you can from your husband, family and friends. Express how important this is to you and that is something you really want to do and that you need them. I recommend joining the teen and adult listserve. The teen and adult listserve is a place where you can post a message and get support or even vent your frustrations via e-mail. To join, e-mail Sarah Foster at [PKUADULT@aol.com](mailto:PKUADULT@aol.com) and tell her you want to join. When I first started my diet, I kept a diary of everything I ate throughout the course of the day. That really helps keep you on track so that you don't go over your limit. It will eventually come natural to you and you won't need to keep a diary. It will be as natural as breathing. Another thing I highly suggest is that you get active with PKU and go to as many functions as you can. It will help keep you focused.

As far as formula coverage, one thing you can do is check into what laws and/or state assistance programs are available to you. Your clinic may also be able to steer you in the right direction as to where to go for assistance. I also recommend contacting Children's PKU Network. They may be able to temporarily supply you with formula upon filling out a crisis intervention application. Their address is 3790 Via De La Valle, Suite 120, Del Mar, CA 92014 and their phone number is (800) 377-6677. You can also go to their website for an application at [www.pkunetwork.org](http://www.pkunetwork.org) and click on crisis intervention applications.

Here is the recipe I use to drink my "milk". I mix 134g of Phenyl-Free 2HP with 80g of Jello INSTANT chocolate pudding powder and 24oz of water. I have tried various recipes for mixing formula and this has been the way I have been drinking it from day one without any problems at all. You will need to check with your dietician to see how much Phenyl-Free 2HP you need and how much of the chocolate pudding you can have. There are many varieties of systems that are available for drinking formula. For example, Phlexy-10 is a combination of powders and capsules. There are also many flavored varieties out there that you can try. Your clinic will be able to help you find the system that is best for you.

Once you start your diet and see what a difference it makes in your life, you will not want to go off diet. You will feel so much better that you will be constantly motivated. Your life will be happier and healthier overall.

Best of luck to you!

Jennifer



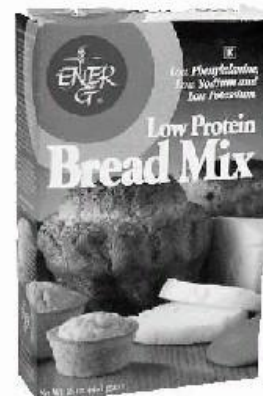
# WHO SAYS RESTRICTIVE DIETS HAVE TO BE BORING?

Ener-G Foods, Inc. offers a wide variety of foods suited to the Low Protein Diet. Some of these products are:

## • Low Protein Pastas •



## • Low Protein Bread Mix •



## • Snacks •



## Other Products Include Our:

- Low Protein Breads
- Low Protein Cheeses
- Cookies
- Flours
- Milk & Egg Substitutes

Call for a free catalogue : 1-800-331-5222  
or visit [www.ener-g.com](http://www.ener-g.com)

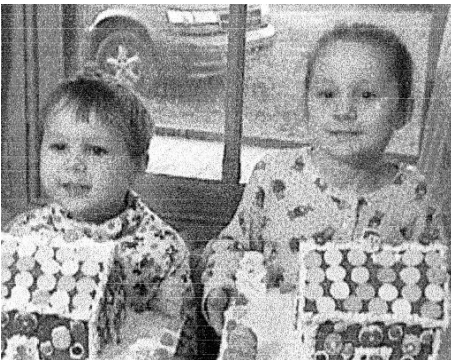


## Grandmas' Corner

Dear Grandma, Now that the holidays are over, do you have any special memories from last year?

We had some wonderful times with our immediate family and with our PKU family. In March of 2002 we attended the NEC conference in New Hampshire, in October, the National Coalition Conference in Orlando and then went to Concord, Massachusetts for a cooking with Cambrooke Foods demonstration

I had a wonderful time making gingerbread houses for my 5 grandchildren for Christmas. They turned out great and the look on the children's' faces when I gave them to them was worth any amount of time and work it took to make them. They really aren't hard to make and so much fun to give.



Stephen and Becca with their houses

The Cooking with Cambrooke demonstration came at a wonderful time for us to have great ideas for Christmas. Lynn Paoletta did a great demonstration and gave us all a lot of really good ideas. The first thing she made was lasagna and since I was planning lasagna for our family for Christmas Eve dinner, it was perfect. Instead of using lasagna noodles for it, she made crepes. and stacked them with the filling in between the layers. We used the flat bread maker (which is available through Cambrooke Foods) to make the crepes, but they can also be made in a small frying pan. The recipe for the lasagna is on their website, but here it is also.

### Ingredients:

2 Cups (200 grams) Cambrooke Foods Mix Quick  
1-Cup Water  
2 cloves of minced garlic  
3 Tbsp. Olive Oil  
8 oz Cambrooke Foods Plain Cream Cheese  
1 1/2 cups of your favorite tomato sauce or spaghetti sauce  
1/4 Cup Cambrooke Foods Mozzarella Shredded Cheese

Heat the Flat Bread Maker. Blend the Mixquick and water in a mixing bowl until smooth. Make 5 large crepes according to the Flat Bread Maker

### Instructions. Cream Cheese Mixture

Sauté the minced garlic in olive oil and cool. Combine the garlic, oil and cream cheese and mix until well blended. In a deep-dish 9-inch pie pan, layer the ingredients in the following order.

Place a few tablespoons of the tomato or spaghetti sauce in the bottom of the pan and spread evenly to cover the pan. Place a crepe on top of the sauce and spread with 1/4 of the cream cheese mixture spreading evenly over the crepe. Add a few more tablespoons of the sauce over the cream cheese mixture and repeat with each layer. Add the sauce to the last crepe and top with the Mozzarella cheese. Bake at 350 degrees for approximately 15 to 20 minutes or until the lasagna is heated through. Serves 6 Total protein 1.9 grams, Phe per serving: 68 mg.

Diane Sullivan was also there and she decided that maybe we should add a Tablespoon or two of Cambrooke's MixQuick to the cream cheese mixture before we put it on the crepes. We did that with the second batch and it turned out great. It made them puff up a little more. Either way, the taste was the same and the teenagers in the group loved it. Lynn let the teenagers help with making the lasagna and that was a great idea. It showed them how easy it was to make and they all had a great time. We had a great group that day. grandchildren and they don't like it, but they loved this recipe and gobbled it up at Christmas

Another great idea was a Tuscan Focaccia Sandwich. Lynn used the Cambrooke Tuscan Pizza crust to make a great sandwich.

### Ingredients:

1 Cambrooke Tuscan Pizza Crust  
4 - 1/4 inch thick each slices of fresh tomato



3 - 1/4 inch thick each slices of grilled portabella mushroom

1 large Romaine Lettuce Leaf

1 Tbsp Salad Dressing (Miracle Whip)

1 Tbsp. Olive Oil

1 tsp Seasoned Garlic Salt

1 pinch fresh (or dried) Rosemary

Directions: Brush each side of the Pizza Crust with olive oil. Sprinkle each side with the seasoned salt and rosemary. Place in broiler oven for 2 minutes each side or until golden brown. Slice the loaf "on-the-flat" (Horizontally), coat with salad dressing on each side and add the sandwich ingredients. Slice sandwich in 4 wedges. Total Protein .5 grams Phe per wedge 20 mg

Of course, you can make the sandwich with any ingredients you like. We all tasted everything and everyone loved everything Lynn prepared. The biggest thing with demonstrations like this is that it gives us great ideas. Truthfully, I never would have thought of making a sandwich out of a pizza shell.

For dessert, Lynn made tiny tarts that were fruit filled and very easy to make. For ingredients, you will need:

2 Cups Cambrooke Foods all purpose baking mix (200gm)

1/2-Cup (85 gm) Cambrooke Plain Cream Cheese

2 Tbsp. Sugar

3 Tbsp Butter

1/8 tsp salt.

Directions: In a food processor combine the All Purpose Baking Mix, sugar, cream cheese and salt. Then pulse 3 to 4 times until the mixture resembles a coarse meal. Gradually add the pieces of butter until the dough forms a ball. Wrap the dough in plastic wrap and refrigerate until firm. Approximate 1 hour.

You can make a piecrust with this or small tarts. For the pie crust, or tartlets, preheat the oven to 425 degrees. Place the dough between two sheets of waxed paper, lightly dusted with the baking mix and roll out to a 13 inch circle about 1/8 inch thick. Fit into a 9-inch pie plate and trim off any excess overhang. Bake for 15 to 20 minutes until just browned than fill with your favorite pie filling.

For tartlets: Lightly spray 10 muffin tins with vegetable oil. Divide the dough into 10 equal pieces. Roll each piece into a ball in the palms of your hands. (Lightly flour your hands). Put 1 ball in the center of each muffin cup. With a wooden tart tamper or a narrow flat bottomed glass, lightly floured, press the dough into the cups until the dough begins coming up the sides of the

cup. Then, twist the tamper to release it. Chill for at least 10 minutes to firm the dough and bake 15 to 20 minutes until just browned. Fill with your favorite pie filling. The tarts may be topped with cool whip or a thin mixture of powdered sugar and creamer.

If you ever get a chance to go to a cooking demonstration please do. Check the Macpad website for an upcoming demonstration. I plan to attend every demonstration that I can. It is fun and informing.

We feel so lucky to have such a large support group with all of our various PKU Groups and now with Cambrooke foods new line, we have so many choices for food that our grandchildren love. It is so nice to have "real" looking food for them. I know I sound like a walking commercial for Cambrooke foods, but we truly love all of their products and appreciate all the hard work that Lynn and David Paoella have done for their children and ours.

Hope your holidays were as good as ours and talk to you all again soon.

Grandma



## MACPAD PICNIC- AUGUST 2, 2003

It is never too early to mark your calendars for our 16<sup>th</sup> Annual MACPAD Picnic! Please circle August 2, 2003 on your calendar and come join us as we get together for good food, friends and fun. Hours will be 12PM to 4PM.

We will again get together at the home of Harvey & Anna Weaver near Denver PA. They have been most hospitable in past years, and are already thinking of this year's picnic.

Any one wishing to contribute any Door Prizes, secondary to our Amish Quilt, please contact MACPAD. We can always use smaller items as PKU Bingo giveaways or at our "Fish Pond" for the children birth to age 12.

More information will come your way and we look forward to another fun time.



### ***A letter from the President***

I am often asked, "What can I do to support MACPAD?" You will find that this year, which will mark the end of MACPAD's 5<sup>th</sup> year as a non-profit organization, there will be many opportunities to support MACPAD and its efforts to assist individuals and families that live with PKU.

Our Genuardi's program has recently changed so that instead of sending in your receipts, you can simply register your Genuardi's Club Card to provide cash back to MACPAD whenever you shop at Genuardi's. You can do this by calling Genuardi's at 1-877-723-3929 or by visiting the e-scrip website at <http://www.escrip.com/affiliates/genuardis/index.html>.

This program is available throughout Pennsylvania, Delaware and New Jersey. MACPAD's Group ID Number is 149572268. We are listed as "Mid-Atlantic Connection for PKU" in escrip's website. If you don't shop at Genuardi's but the supermarket that you shop at has a similar program, let us know so that we can sign up. This is a very easy way for you to support our organization.

This spring, MACPAD will hold its second annual Walk for PKU. This walk will be held in South Jersey (at the Washington Lake Park in Sewell, NJ). Please plan to attend or make a donation. The proceeds from this walk will be used to support PKU research.

We are always looking for topics, articles or information to include in our quarterly newsletter. Why don't you help out our Newsletter Editor by sending in your favorite recipe, a story about how you deal with PKU, a question for one of our columns, or a topic for a future article?

Only with your participation can we guarantee the success of MACPAD! If you want to know how you can help support MACPAD, you no longer need to ask, just

do it!

Thanks.

Judy Griffith



### **Happy Birthday To Our MACPAD Friends**

Dennis Blouch	January 31
Stephan Bodden	February 8
Jada Boyd	March 14
Amanda Bracero	March 5
Sara Brinsfield	January 30
David Dawa	January 8
Lane Chabarría	March 2
David Esh	February 8
Mary Fisher	February 11
Daniel Gilbert	February 28
Jacob Graver	February 25
Madison Hostetler	February 9
Maria Kamarados	January 15
Rebecca Lehman	March 12
Robert Schreck	March 2
Heather Matthews	January 16
Julie McMullin	March 6
Courtney Unger	February 1
Rose Mularadelis	March 8
Abigail Myers	March 9
Greg Orris	February 20
Rebecca Phillips	January 2
Michael Chirigos	February 9
Greg Reynolds	January 27
Devon Resnick	March 20
Levi Stasney	January 21
Christian Thornton	March 10
Sherif Ismai	March 9

---

*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.*

## **\$5,000 Signing Bonus**

By Nicole Walters, RD at Children's Hospital of Pittsburgh

Did that headline get your attention? Typically we associate signing bonuses with athletes and top executives, but now this is one of the incentives used by facilities to attract nurses. The nursing shortage problem has the potential of hitting a population near and dear to all of us.

Since this is my first time writing, let me introduce myself. My name is Nicole Walters and I am the metabolic dietitian for the PKU clinic at Children's Hospital of Pittsburgh. I have been at this clinic for almost 3 years and have had the opportunity to meet many wonderful families and professionals.

Our clinic follows approximately 100 patients 'on diet' and hundreds of others that are 'off diet'. We have patients referred to us from 25 counties in Western Pennsylvania. At our Pittsburgh PKU clinic, we are very fortunate to have community health nurses that are still quite involved with our patients and families, despite the overwhelming demands on their time.

When a newborn screens positive for PKU, the nurses are generally the first representatives of our clinic to meet the new family. They often visit the home to perform confirmatory blood specimens, provide 'face to face' basic education, and also to supply the metabolic formula and gram scales. The nurse will go into the home of the newborn to perform weekly blood tests and supply formula for the first several months until the family can be educated to perform these tests independently.

This is the basic 'job description' of a community health nurse providing care for a patient with PKU. However, I have worked with some nurses who have gone above and beyond this to literally save lives of children with PKU. My first experience with one of these *super nurses* happened in my first year of working in the PKU clinic. I had a family with 2 children that were having significant difficulties in managing the diet; the children had phenylalanine levels consistently greater than 20. This nurse visited the home at least weekly, helped the family with menu planning, and referred the parents to community support programs. After much intervention, these children are currently doing much better in school and have excellent blood phenylalanine control.

We have nurses who have lobbied for excess state funding to be used for gram scales, books, and low-protein foods for needy families. A 'team' of two dedicated nurses has been visiting one family every week for almost 3 years to provide much needed support for a family struggling with the difficulty of managing the PKU diet. There are even some nurses who have been involved with patients with PKU from their birth to the birth of their children.

Since many families live several miles from a clinic, the nurses are an essential link in the community. They are a vital extension of the PKU clinic staff to provide much needed support to families living with PKU.



Due to overwhelming demand for PKU handheld device software, we have designed a phe database for palm pilots that is now available as a free download.

Order PKULife 1.0 software and, for a limited time only, every order of PKULife 1.0 software will be shipped with a FREE mini flip-top personal calculator (while supplies last).

For additional information log onto [www.pkulife.com](http://www.pkulife.com) or call 610-983-9939.

**Following is an announcement regarding the PKU Teen Adult Conference in July**

Dear Editor,

I am overjoyed to inform you that the National Coalition for PKU and Allied Disorders will be hosting a National PKU Teen and Adult Conference. The agenda of the conference is the result of much discussion on the Teen Adult PKU Listserv.

Because of its nature, the conference is only open to PKU Teens & Adults, Parents of PKU Teens & Adults, Spouses/siblings, etc. of PKU Teens & Adults, and healthcare professionals involved in the treatment of PKU. Below are some details about the conference as well as a contact for more information.

Event: National PKU Teen and Adult Conference

When: Friday, July 25 and Saturday, July 26, 2003

Where: Crowne Plaza Hotel & Resort at the Crossings, 801 Greenwich Avenue, Warwick, RI 02886

Room Rate: \$89 per night

Conference Fee: \$50 per person (includes lo and high phe breakfast and lunch both days)

Contact for additional information: Trish Mullaley, President National Coalition for PKU and Allied Disorders

coalition4pkoad@aol.com

877-996-2723

www.pku-allieddisorders.org

Many adults and teens with PKU (myself included) have complained "there's nothing for us." Well, now there is!

I hope to see many of your readers there!

Sarah Foster

PKU age 32

Boston, MA, USA

---

Here is a great recipe for **Potato Nachos** which appeared in **Creative Family Cooking**, the **MACPAD** Cookbook ( page 46)



	Mg phe
1 small (80 Gm) potato, thinly sliced	73
½ oz. (17 Gm) lo pro shredded cheddar cheese	24
¼ tsp. salt	0
¼ cup (60 Gm) Old El Paso Homestyle Chunky Salsa	20
1 Tbsp. (8 Gm) green chiles, chopped and drained	5
1 Tbsp. (12 Gm) green onions, chopped	4

Total phe per recipe	126 mg
Total yield	2 servings
Phe per serving	63 mg

Arrange potato slices in a microwave safe pie plate or shallow baking dish. Sprinkle slices with salt, and then brush with half of the salsa. Cover and microwave on high 4-5 minutes or until potatoes are tender, rotating plate a half turn after 2 minutes. Brush potato slices with remaining salsa. Sprinkle with green chiles, onion and cheese. Cover and microwave on high for 30-60 seconds or until cheese melts. Serve immediately.



## T I N S

  
P

  
A

  
D

  
W

TINS FILLED WITH 1 LB OF LOW PROTEIN  
PRETZELS \$8.50 PLUS SHIPPING

## B A G S

8 OZ BAG	\$ 2.25
9 – 8OZ BAGS IN CASE	\$20.25
1 POUND POLY	\$ 4.50
2 POUND BAG	\$ 7.55
2 – 2 POUND BAGS	\$15.10
PRICES PLUS SHIPPING	

## 50 CENTS OFF ANY ORDER

### 1-800-683-8375

**Mention PKU Newsletter  
for discount**

**5 mg of PHE per 28 grams pretzel**

**Prices good until 5-31-03**

  
G

  
S

  
C

  
F

TINS FILLED WITH 2 LB OF LOW PROTEIN  
PRETZELS \$12.60 PLUS SHIPPING



Uncle Henry's Pretzel Bakery

P O Box 219

Bowmansville, PA 17507

[www.unclehenry.com](http://www.unclehenry.com)



### The Popcorn Polka

“Dancing” popcorn kernels are fun and easy! You’ll need a tall glass and a smaller glass. One heaping Tbsp. Baking powder, 1 Tbsp. Vinegar, water and a few popcorn kernels. Pour the vinegar into the small glass and the baking soda in the tall glass. Add water to the small glass(vinegar) to fill. Working over a sink, pour the vinegar/water solution into the tall glass. When the bubbling subsides drop the popcorn kernels, one by one into the glass. In a few moments, the popcorn kernels will “dance”! (If the dancing slows down, add another Tbsp of vinegar to liven things up again!

**Warning:** These “ingredients” should not be eaten or used in any other way than described.



**Roasted red pepper and asparagus sauce** is great on any pasta! This recipe was also in **Creative Family Cooking**, the MACPAD Cookbook,( page 32).

	Mg phe
1 (350 Gm) red pepper	100
1 bunch (155 Gm) asparagus	93
1 tsp. salt	0
½ cup Swanson's vegetable broth	0
2 tsp. olive oil	0
1 small clove (3 Gm) garlic	5
½ tsp. balsamic vinegar	0
1/8 tsp. cayenne pepper	0
2 tsp. thyme	0
½ cup lo pro pasta per serving	

Total phe per recipe (Excluding pasta)	198 mg
Total yield	6 servings
Phe per serving	33 mg

Preheat oven to 500 degrees. Roast peppers and asparagus 10 minutes. Remove asparagus when it is bright green and turn peppers. Roast pepper an additional 10-15 minutes until tender. Let peppers cool. Slice asparagus into 1-2" pieces. Remove skin and seeds from peppers. In blender, blend peppers olive oil, broth, garlic, vinegar, cayenne pepper, salt and thyme. Pour sauce over lo pro pasta and mix in asparagus.



### Helpful Hints when planning meals for your young child.

When your child begins eating and you want to be very accurate with the phe calculations, weigh the food plus the dish and when finished, weigh the dish again so that you will know exactly how much food was eaten by subtracting the final weight from the initial weight. NOTE: This only works when there is only one food in each dish.

Keep plenty of canned and frozen vegetables around for quick meal preparation for toddlers. Canned veggies are great for young toddlers because they are easy to chew.

In the spring and summer, stock up on fresh fruit, especially bananas, strawberries, watermelon, honeydew, cantaloupe and blueberries. The rest of the year you can use bananas, oranges and apples.

Use Apple Jacks, Kix , Lucky Charms or Fruit Loops (instead of Cheerios) as an easy breakfast or snack.

Serve a fruit and vegetable at lunch and dinner as much as possible. It helps to get the child used to eating them, which will help when their appetites increase later on.

Freeze any leftover gravy or sauce in ice cube trays (when frozen place in plastic bag with label)

Pre-weigh and bag dry ingredients for recipes that you make a lot.

Pre-weigh snacks so that they are available quickly. This is especially helpful on long trips. One great example, is to pre-weigh Pringles, put them in plastic bags and return the bags to the Pringles container.

Keep a list of the foods that your child commonly eats (use the charts at the end of this section); Refer to the chart often.

Only make half a recipe the first time you make it; this will save time and cut down on the waste.

---

*Editors Note: The previous recipes and helpful hints were reprinted by request. If you would like to request the reprint of another recipe (from **Creative Family Cooking**) please contact **MACPAD**. You may contact us at P.O. Box 6086, Lancaster, PA 17607, call 717-872-7546 or visit our new website [www.macpad.org](http://www.macpad.org) for ordering information.*

---

**Auction Dates** Each fall auctions are held to benefit The Clinic For Special Children in Strasburg, PA. Amish quilts, handmade furniture and various crafts and foods are sold or auctioned. The dates for this year are September 20 in Leola, September 6 in Blair County and mid-July in Shippensburg. For more information contact **MACPAD, at the above addresses** or the Clinic at 717-687-9407

---



1248 Sussex Turnpike  
Unit C-2  
Randolph, NJ 07869

Toll Free: 1-888-640-2800

Fax: 1-973-895-3742

**COUPON VALUE \$5.00 OFF YOUR NEXT ORDER  
OF \$50.00 OR MORE!!**

**NEW PRODUCTS! Call for information about OHZ and SPANISH RICE!!**

Thank you: From the Dietary Specialties Team

Coupon No: MACPAD

Coupon Expires: 06/03 (limit one per family) Sorry, coupon can not be used with web orders.





**The Dietary Shoppe, Inc.  
184A East Evergreen Avenue  
Philadelphia, PA 19118  
215-242-5302**

**NEW PRODUCTS AVAILABLE**

**Aproten Biscotti  
Cerrone Waffle Cones  
DS Herb & Garlic Ziti**

Order by Phone or Website or Stop by.

Hours: Tuesday—Saturday 10-5:30 pm

Gift Baskets & Gift Certificates Available.

Visit our new website <http://dietaryshoppe.com>



Address: P.O. Box 6086  
Lancaster PA 17607  
Phone: 717-872-7546  
Email: [Info@MACPAD.org](mailto:Info@MACPAD.org)  
Website: [www.MACPAD.org](http://www.MACPAD.org)

**Newsletter Contributors**

Judy Griffith, Nicole Walters, Victoria Nicoli,  
Sharon Johnstone, Jennifer Burkel, Karen  
Blackbird, Sarah Foster, Janice Paterno, Cindy  
Hoover and Peg Lunt

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

**Mid-Atlantic Connection  
For PKU and Allied Disorders, Inc**

**Officers**

**President**

Judith Griffith

**Vice President**

Ken Barton

**Secretary**

Sharon Johnstone

**Treasurer**

Robert Johnstone

**Board of Directors**

Carol Barton

Lynn Trump

Christy Schulze

Laura Assayag

Janice Paterno

Deb Gilliano

**Honorary Board Members**

Karen Blackbird

Linda Tonyes

Ann Starr