



## A Message From the MACPAD President

### SEEDS OF CHANGE

As I write this letter, our organization has been in existence for just over three years. During this time we have gone through some rough patches and we have experienced some growing pains. With the support of many families in the area (and some outside of the area) we have watched MACPAD grow into a real support group. The board believes that we have raised enough funds over these three years to be able to re-evaluate our position on requiring membership dues.

In order to be able to reach more families and achieve greater goals for the organization, the Board of Directors has recently voted to remove the membership dues requirement and to open membership up to all families residing in the mid-Atlantic region. Families living outside of the mid-Atlantic region can continue to be included on our mailing list, but we may have special activities or privileges that are available only for members.

Because of this change, we will lose one of our main sources of income. We hope that our families will see the value of our  
(Cont. on page 7)

## Coming Soon Fourteenth Annual Picnic!

Come one, come all! Mark your calendars for the 14<sup>th</sup> Annual pku picnic! Our annual picnic is scheduled for AUGUST 4, 2001 from 12pm to 4pm at the Weavers Farm in Denver, PA. For those of you who have attended the picnic before, we welcome you back for a day of fun, games, food and socialization.. For those of you who have not previously attended our picnic, we look forward to meeting you and having you and your family enjoy the day.

We offer our Low Protein buffet (the highlight of the picnic); a Quilt raffle (made by Lancaster County women who donate their time and talent) Below is the pattern for this years quilt: A queen size "Amish Bears Paw in A Cabin" design.

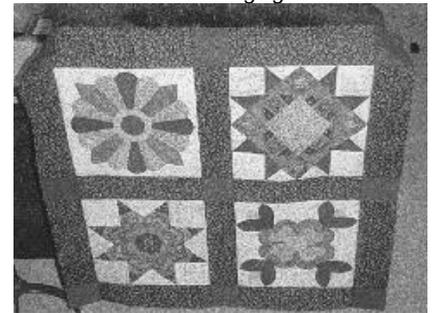


The picnic will feature: PKU Bingo with prizes, an old fashioned "fishing pond" (with prizes) for the children; raffle prizes (including a wall hanging donated by Lynn Trump (co-chair of the picnic); pony rides; games and entertainment for the kids; hayrides, generously provided by the Weaver Family and the opportunity to meet and talk with

other PKU families from across Pennsylvania and adjoining states.

For our low protein buffet, we generally ask our families to bring something everyone can share. So please give some thought to what you would like to bring along and we will contact you at a later date.

*Handmade wall hanging for raffle*



The Weavers Farm is located in Denver, Pa at 1178 Dry Tavern Road. Directions are included in this newsletter.

We are still in the planning stages and open to any and all suggestions. If anyone has anything he or she would like to suggest, please contact:

Carol Barton at  
email: Cabbi5409@aol.com; phone (717) 285-0543 (evenings or leave a message) or Lynn Trump; phone 717-866-2968; mail: 921 Hilltop Road, Myerstown, PA 17067



Congratulations to Harlan and Marlene Fox on the birth of their new daughter, Diann!

# Random Reflections

I read a Dutch poem that all parents can identify with as they watch their children grow and mature. "The gem cannot be polished without friction nor man perfected without trials."

As I think about the struggles that accompany raising a child with special food needs, the PKU diet could be viewed as one of those "surprise" struggles in raising your child. However, as I reflect on the diet, it has merit that will assist your child to be a very healthy adult as well as teaching the rewards of healthy eating...even if not by choice. Most of us are privileged to make "choices" about the food that we want and when we want them. A PKU child does not have that freedom.

Depending on the age of the child, there are times that the parent must make the "best" choice for the child. Give your child some food choices whenever possible. When children feel they have control of some things, they are more willing to learn to do the right thing! Choices have consequences. The earlier that a child has this explained to them, the better for the child in ALL aspects of his or her life. PKU having a defined blood level to strive for provides the child with PKU and their family with their goal!

A nugget of wisdom...give your child some food choices whenever possible...and as early as possible. We all know that the more food choices that a person with PKU has, the better. Explore with them the process of "tasting and trying" new fruits and vegetables. even ones that are NOT YOUR favorites, because they may become theirs. Model

"healthy choices". Kiwi, spinach and figs were early favorites of our son. They provide a host of vitamins and nutrients.

With spring arriving, consider planting a strawberry plant and a cherry tomato plant with your child. Educate your child to all of their choices. If it is not possible for you to plant your own, visit a produce stand or farmer's market. Maybe even find a strawberry patch and pick your own!

The fruits of your labor will be ever so sweet! and in the process you and your child with PKU will discover that what may have seemed like a struggle of making choices is really not a struggle but a joy!

Happy Spring, Cindi Hoover

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# Thanks!

To everyone who has been saving their Genuardis receipts! MACPAD has been the recipient of almost \$ 400.00 since this "cash-back" program began! Genuardis, a family owned and operated local grocery store, refunds 1% of your grocery receipt total to MACPAD. They also generously sponsored The Phillie Fanatic at last years picnic. So, patronize your local Genuardis and help MACPAD at the same time. Just mail your Genuardis receipts to MACPAD and we'll do the rest!

## Happy Birthday To Our MACPAD Members!!



Jessica Smith - May 28  
Rebecca Schulze - June 3  
Christine Nicole - July 15  
Jacob Smith - July 16  
Corey Kirby - July 17  
Charles Griffith - July 20  
Jessica Shooter - August 1  
Eric Johnson - August 16  
Deidra Kline - August 19  
Logan Royer - August 18

### Editors Note:

*The mission of MACPAD is to enrich the lives of individuals and families of individuals with metabolic disorders by disseminating information and encouraging the exchange of ideas. This newsletter serves as a vehicle to that end. We encourage any individual who would like to share their story or experience with a metabolic disorder to submit an article to Connections. All submissions should be mailed to MACPAD, P.O. Box 6086, Lancaster, PA 17603. While we cannot promise every story will be published, we can promise every story will be considered.*



## **IT'S NOT WHAT YOUR GIVEN, BUT WHAT YOU DO WITH IT!**

Two years ago my granddaughter Mary Elizabeth Butler was born. The love I feel for her was instant the moment I saw her! Becoming a "Maw-Maw" has been one of the greatest events of my life! We we're so relieved that everything went so well with her birth and that our granddaughter was just perfect. On the third day of her life, we got the call from the hospital asking us to retest her for PKU. Of course my daughter said: "What is PKU?" All she heard during that phone call was the words, no protein, and mental retardation. I happened to be in the room when she got the news that Mary Elizabeth tested positive for PKU. My daughter was just devastated and started to cry and she said, "She'll never have a birthday cake!" My response was "Oh yes she will, somehow, someway". It's interesting how grandparents will go to the end of the earth for their grandchildren.

After we got over the initial shock, I as her grandmother started to blame myself. I asked myself questions like "What genes have I given my daughter?" That was a very hard thing for me to come to terms with. I did not know of anyone in our family who had ever had PKU! Finally acceptance set in and we began to realize that it truly was only a diet. Not an easy one but there are worse afflictions. We realized that she would grow up to be a normal child. I have to admit that even as a baby her diet was challenging, like eating buttered mushrooms for breakfast. But hey, who said mushrooms were only for dinner? She particularly loves her BABA or her medical formula. She is now learning to drink her formula from a BABA cup. She is very attached to it and we find that when she is really irritable and having a meltdown her medical formula helps to stabilize her. Her favorite foods are pasta, macaroni and cheese and olives. Like any toddler, she shares with her doggie friends Sam and Sweet Pea.

It is a little trying to be mobile and carefree with a special diet child. But somehow we always manage. We carry a small cooler just about everywhere we go with her "milk" and special foods. We've learned to adapt at restaurants and order things that she can eat partially if not completely. We really try to make her seem just the same as everyone else. By the way, she also goes to McDonalds just like the other kids and orders lemonade and fries!

She is treated by the Univ. of Miami and her nutritionist adjusts her Phe weekly. Her mother has really learned how to manage her diet daily and she even enjoys a lot of the same foods that other children do. She relies a lot on Virginia Shuett's books and tries the recipes in the cookbooks and is getting really good at baking bread! She even knows how to make her an "omelet" with egg replacer.

My daughter Elaine and son-in-law Greg are great parents! They have been given a great burden in their young lives. But I believe that God gives the "special ones" to those that can handle it. I am very proud of them.

Mary Elizabeth, aka Mimi, is doing all the normal things that two year olds do. Yes, throwing tantrums! She takes swimming lessons, attends gymnastics and loves to swing and ride her bike! She will be going to pre-school this fall for four hours a week. She already knows her address, full name and ABC's. Proof that the diet works. Nothing wrong with this brain! Now if we can only master potty training!

How far we have come since that fateful day when we thought our world was ending! Life goes on with a beautiful, smart, silly little angel called Mimi or Beauty Girl or Mary Elizabeth who just happens to have PKU! I hope that by reading this letter I've encouraged you and given you some insight into the life of a PKU child. Thanks for the opportunity to share our story! Our lives are deeply blessed!!!

Yours Truly,  
Marylou Ott

**P.S. *She's had a beautiful birthday cake for all her birthdays!***



**ENER-G FOODS, INC.**

ENER-G LOW-PROTEIN & LOW-PHENYLALANINE HIGHLIGHTS. REASONABLY PRICED & READY TO SHIP!

Product	Item #	Net Weight per package	Serving	Protein (g) per Serving	Phenylalanine per Serving	Price per package (shipping not included)	Minus 15% Discount
Low-Protein Bread Mix	1314	16oz. (454g)	1 cup (108g)	.28g	6.8mg	\$3.40	\$2.89
Thin Slice Tapioca Bread	4015	17.5oz. (496g)	1 slice (31g)	.13g	32mg	\$3.99	No Discount
Wheat Starch	1316	5lb(2270g)	1 cup(128g)	.4g	6mg	\$4.49	\$3.82
Rice Starch Loaf	4040	21oz. (600g)	1 slice (50g)	.59g	20mg	\$5.40	\$4.59

## Uncle Henry's Pretzels

Uncle Henry's is currently experimenting to make the low protein pretzel with less breakage. We thank you for your Patience as try to make this pretzel better in the next several months. We have been getting a number of calls regarding the amount of Phe and Leucine in our pretzels.

Here is the information:

<b>Per 36 grams</b>	<b>per ounce</b>
9 mg of phe	7 mg of phe
17 mg of leucine	13 mg of leucine

Get a 2 lb bag of low protein pretzels through July 1, 2001 for \$7.25. Regularly priced at \$7.55. Mention this ad to receive your special price.

**Uncle Henry's Pretzel Bakery** 717-445-4690

## Lo Phe on the Run



Linda Tonyes RD, St.  
Christopher's Hospital for  
Children PKU Treatment  
Center

The school year is winding down, and the weather is ideal for travel, camping, and vacations. The low phe diet can be managed with careful thought and a few tips. Set out your medical food supplies and equipment for preparation and storage. Take extra in case there is a delay in your return. Pack unopened cans of medical food in carry-on luggage. Pre-measured baggies of powder could raise questions at customs points if you are traveling outside the US. For international travel, carry a letter of medical necessity from your PKU physician verifying diagnosis, treatment, and required supplies. Attempt to avoid exposure of medical food powder to extreme heat. A shaker or a small battery operated single beater (measuring 1" by 6") available from Nutri-Systems are convenient and save space. There could be times when you do not have access to electricity, so simple preparation is best. A soft-sided compact thermal cooler with the "blue packs" which require freezing ahead is a good choice. Another option is a compact stainless steel thermos such as Nissen brand, which can be found at camping stores. This better brand of thermos keeps beverages at the desired temperature, and some models have a convenient

shoulder strap for day travel. Consider the purchase of bottled water to mix with your powder when away from home. The water in some areas has an unfamiliar, unpleasant taste, which can affect the taste of your medical food. Consult with your dietitian about alternative forms such as PhenylAde Amino Acid bars, PhenylAde Amino Acid Blend, or Phlexy-10 system (capsules, bars, or drink mix packets). Call your hotel and tell them you need a refrigerator for a medically prescribed diet. One of the most important steps in planning is to set a schedule for consuming your medical food and stick to it. It will be easy to forget when you are busy.

It is always to your advantage to investigate local restaurants and stores in advance. The Internet can quicken your search as well as assist with inquiries. Talk to other families who have experienced the same type of travel for expert advice. When you book air travel, inquire about vegan (no animal protein) meals or give examples of allowed items such as salads, fruit plate, or potato or rice and vegetable. Make a follow-up call a few days prior to your departure to double-check any requests. Plan to eat one or two meals out and take foods with you for a snack and the remaining meals. Carry a few foods with you at all times to cover delays or a change in plans. This will help to keep you within your prescribed daily phenylalanine exchanges.

Some suggestions for convenience pre-packaged items are: vending-machine size bags of potato chips, apple chips, banana chips, Wise onion rings, or popcorn, snack boxes of raisins, Uncle Henry's low pro hard pretzels, rice cakes, fruit (snack cups, fresh, or dried), small bags of cotton candy, Del Monte's gel snacks, Hunt's lemon pudding, fruit roll-ups and fruit snacks, snack

boxes of cereal, or Loprofin cereal loops. Some agricultural areas as well as foreign destinations do not permit travelers to bring fresh produce; instead travel with sealed tins of fruits and vegetables. Arrange for a fresh fruit basket to be delivered to your hotel room upon your arrival. Fresh fruit is a nutritious and welcome snack for everyone. Restaurants or cafeterias have single-serving packets of saltines, graham crackers, and jelly or catsup packets, which can be tucked into your jacket pocket. G Washington broth foil packets are easily dissolved in hot water for a quick soup. Manischewitz Passover Gold Instant Soup, vegetarian tomato flavor, is a good choice for a cup of soup with 16 mg phenylalanine and 100 Calories per container. Just add hot water. Tang beverage powder makes an easy phe-free morning beverage. Powdered non-dairy creamer such as Vance's Dari-free or Coffeemate can be mixed and added to cereal. Although miniature donuts or pop-tarts are higher phenylalanine items, they are convenient for travel. Take more items than you think you will need.

For special destinations such as a cruise, ask for a cabin with a mini-bar. Empty the mini-bar to store your medical foods and carry-on foods. If you cannot obtain a minibar, ask the cabin steward for a bucket of ice to cool your daily medical food. Use a mini-Tupperware shaker for preparing single portions of medical food. Send a brief description of allowed foods, and resend this request approximately 4 weeks prior to your cruise. Ask for single serving boxed cereals, which are the lowest in phenylalanine. Ask for Italian ice, a low phe dessert. Tropical fruits, melons, and sorbets are other delicious desserts. Inform your server that you wish to avoid chocolate desserts and

gourmet seafood sorbets (one flavor is shrimp!) Use the salad makings (lettuce, tomato, onion) for sandwich makings. Bring Ener-G low protein breads in the convenient 2 slice vacuum cellophane packs. These bread packets have a 6-month shelf life. Ask your server to toast the bread. Catsup, mustard, or jelly are easy sandwich spreads. A variety of grilled or steamed vegetables, potatoes (french fried or baked), and sautéed onions and/or mushrooms can be used for supper. Fruit punch, soda, and water are always available. Bring snack-pack applesauce, low protein cookies and crackers, low protein dinner rolls, and Trader Joe's wheat-free frozen waffles to supplement your meals. Put your breads into sturdy shoeboxes when you pack to avoid crushing it. Low protein rice and pasta can be provided to your chef to prepare. Some families prefer measuring cups and spoons to their gram scale when traveling, because these utensils tend to attract less attention from others. Pack a backpack with a daily portion of medical food, shaker, bottled water, and low phe snacks for day excursions when the boat ports.

Disney World is always a favorite destination. A variety of tips, personal stories, and diet tips contributed by families can be accessed through [www.pkunew.org](http://www.pkunew.org). Click the diet-related box on the home page. Choose "Tips for Management from PKU Families". Then, select "Travel and Dining Out"; scroll down to Visiting Disney World, which appears highlighted within the text. "Travel and PKU Diet" and "Tips for Visiting Disney World" are packed with insight. You can also visit [www.DisneyWorld.com](http://www.DisneyWorld.com) where you can email your questions or call 1-407-W-DISNEY and ask to speak with the nutritionist in the special needs

department. Call WDW-DINE to make meal reservation; the policy is 48 hours notice for dietary requests. They will purchase low protein pasta for preparation when given additional notice.

If you are visiting friends or family in the US, consider mailing your medical food to them in enough time to ensure early arrival. Be certain to put insurance on your shipment. Send a description of allowed foods as well as the foods, which you intend to bring including favorite low phe recipes. This provides your family and friends with the opportunity to coordinate meals with the low phe diet. Bring low protein pizza shells, low pro bread, and low pro muffins in your soft-sided insulated carry-on bag for your final destination. Include low protein pasta or rice.

For weeklong camps, plan ahead by obtaining the menu and then contact the chef to arrange substitutions. Make your low phe menu as similar as possible to the regular menu. Remember bottled water for preparing the medical food. Don't forget marshmallows for toasting. Consider kosher marshmallows which can be phenylalanine-free because they are made with pectin instead of gelatin.

Use travel as a practice to sharpen self-management skills. Don't forget your sunglasses and the bug repellent. Above all, have fun.

The author wishes to acknowledge the advice of the following families in the preparation of this article: The Schulze family (international travel), the Madera family (camping and shore trips), the Harrison family (air travel within the US), and the Byrne family (cruise tips).



### **The Dietary Specialties Shoppe, Inc.**

Not to be confused with Dietary Specialties-Menu-Direct, although they have a similar name, they are a separate entity. Owned and operated by a Registered Dietitian, Chelsea Smith. MS.RD.CDE, who saw the need and wanted to take a different path in her career. They cater to those with special dietary needs such as Gluten Free, Sugar Free, Low Sodium, Casein/Dairy Free and Low Protein restrictions. Their mission is to provide a resource that is comprehensive and offers more food choices to many that have limited selections. Their One Year Anniversary has just gone by and they have received a great response from the community. In the last few months the Low Protein product line has expanded greatly and consists of products by Loprofin, Aglutella, Juvella, Ener-G and Energy Options. These and more are available by phone-215-242-5302, through [www.dietaryshoppe.com](http://www.dietaryshoppe.com) or in person at the retail store-184A East Evergreen Avenue, Philadelphia, PA 19118. Store hours are Tuesday – Saturday 10:00am-6:00pm.

**NEWS FROM SHS NORTH AMERICA**

**New product.** SHS North America is pleased to announce a new addition to the Loprofin product range. We now offer **Loprofin Drink Mix!** One 14 oz. can of **Loprofin Drink Mix** makes more than 5 quarts. It can be added to **Loprofin Cereal** loops or used in everyday cooking and baking. Check out the website, [www.shsna.com](http://www.shsna.com), for recipe ideas using the **Loprofin Drink Mix.**

For more information please call 1-888- LOPROGO.

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(Cont. from page 1)

organization and continue to support us financially (with donations) and with their time. We also hope that we can continue to provide this newsletter free of charge, but depending on our success with other fundraisers, we may at some time need to begin charging for printing and mailing costs.

We are asking everyone who would like to become or remain a member of MACPAD to please complete the application form that is included in this newsletter. We need to update our records.  
Thanks!

Judy Griffith, President  
Mother of 3 boys, 2 with PKU

Editors note: For your convenience simply fill out the form on page 9, remove from this newsletter, fold in thirds, add stamp and mail.



### Grandma's Corner

Are you a grandmother of a child with a metabolic disorder? Ever have a question and you just can't decide on the answer? Wish you could talk to your Grandma?

This column will feature questions that our readers send in. The questions will be given to a panel of grandmothers and the answers will appear in the next issue. So send your questions to MACPAD.

Should I worry if my grandchild is sick and doesn't eat or drink their formula?

Recently my granddaughter was in the hospital and didn't eat or drink for a week. Our family was worried about how high her levels would go and I posted a message to the list serve asking for help. I had tons of wonderful answers and the consensus was "treat the illness first then worry about the levels". The consensus of opinion was that her levels would hit at least 30, but luckily they only went up to 12. She normally runs around 3-5. Dr. Richard Koch said that we didn't have to worry about short-term raises in levels, as long as they come down after the illness.

She recovered from her illness and her levels are now back to normal.

At what age should my

grandchild stop taking a bottle?

When my 15-month-old grandson had his regular check up, they recommended that he stop taking the bottle by 15 months and begin using a cup. They said also that we shouldn't worry if he refuses to drink his formula for a few days as it is better to take the bottle away than to worry about drinking the formula for a few days. It is best to start giving the formula in a cup anytime after 6 months, or when the child is able to drink out of a cup. We feel it is good to give the formula in an open cup for the child to get used to the smell of the formula. I did run into a problem recently when my grandson bit the top of the nipple off of his bottle and I had to give him his formula in cup. I normally give it to him in an open cup and without realizing it; I had given him his juice in a sippy cup. When I put the formula in a sippy cup, he took one taste and let it all run out of his mouth and wouldn't drink it at all. I now realize he associated his formula with either his bottle or an open cup and his juice with a sippy cup. I now think the best idea is to give him his formula in both styles of cups from the beginning to eliminate this problem in the future.

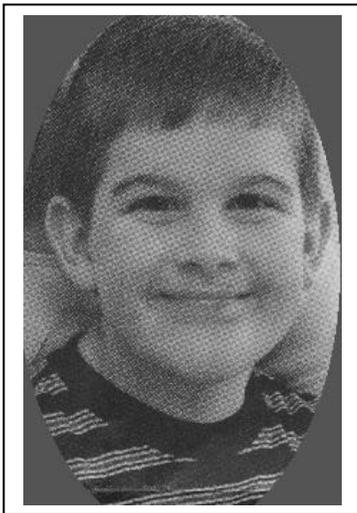
How do you get a child to eat a snack that they have decided they don't like?

Recently, we got some of the tapioca cakes from Cambrooke Foods. They are really good and my grandson loves them, but my granddaughter took one look at them and decided she didn't like them without even tasting

them. I decided to melt some almond bark and dip the tops of the tapioca cakes in it. There isn't that much phe as the cakes are phe free and she now thinks they are wonderful cookies. To make them less phe, you can dip them in the white bark and maybe add a few sprinkles on top to make them look more festive.

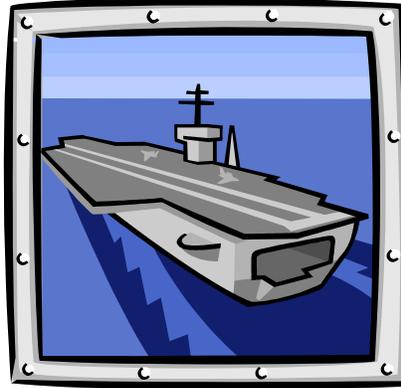
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Kenny Barton, 9-year-old Lancaster boy with PKU has recently been chosen as the Ambassador child for the Lancaster County March of Dimes.



Kenny, who is shown in the Lancaster, PA New Era newspaper (photo by Marty Heisey) will spend time traveling to local schools to talk about PKU and how it affects his life. Kenny participated in the April 29 March of Dimes WalkAmerica to publicize the fight against birth defects.

Kenny's dad, Ken Barton is the Vice President of MACPAD and his aunt, Carol Barton is on the Board of Directors.



### JOIN US ON A PKU FAMILY AND FRIENDS CRUISE

Our friend Pat Byrne has been busy planning a cruise for family and friends of people with PKU (and other metabolic disorders). Pat, along with Cruise Holidays, has reserved space on a 4-night cruise departing from New York going to Halifax, Nova Scotia on July 18, 2002. We will cruise on the Carnival Cruise Line ship Triumph.

Pat has been working with the Food and Beverage Director for Carnival to coordinate a vacation that will provide low protein alternatives at every meal served in the dining room. There will be low protein pastas, breads, pancakes, bagels, burgers, and pizza. Salads, fruits, and vegetables are also available. Based on a survey of all families attending the cruise, Pat will work to coordinate the specific foods that will be shipped and prepared for us during the cruise.

If you would like to join us on this cruise event, please contact Pat Byrne for further information. You will need to provide a deposit before June 25, 2001 in order to reserve your cabin at the special low rate that Carnival has promised us.

Pat has a 13-year old daughter Krista, who has PKU. They have planned this event so that families can meet each other and interact in a fun environment without having it focused on education, meetings, and cooking classes for PKU. Come, enjoy, relax and don't worry about the food!!

You can reach Pat at (610) 277-6850 or by email [wecruise@bellatlantic.net](mailto:wecruise@bellatlantic.net). But HURRY -- space is limited!

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### PKU Life

PKULife is the first software application designed to benefit those managing the PKU diet (Phenylketonuria). PKULife helps individuals with PKU and their caregivers with daily diet tasks, such as daily intake, meal planning, phe calculation, recipe calculations, food searching and more.

PKULife was developed using specifications from people who actually manage the PKU diet. Before it was released, PKULife 1.0 was beta tested for over 4 months, resulting in great excitement from our beta testers. Since PKULife was released, we have received great responses from people who are actually using PKULife on a daily basis.

Order your copy of PKULife today and receive free first class shipping. You save \$4.95. Order online at [www.pkulife.com](http://www.pkulife.com).

# The Mid-Atlantic Connection for PKU and Allied Disorders, Inc

Please add me to your...

Membership List (PA, DE, NJ)  
Mailing List (all other states)

To become a member of MACPAD or to be included on our mailing list, complete the form below and mail to:

**MACPAD Membership P.O. Box 6086 Lancaster PA 17607**

Name	_____
Street address	_____
Address (cont.)	_____
City	_____
State/Province	_____
Zip/Postal code	_____
Country	_____
Home Phone	_____
E-mail	_____
Name of person(s) with metabolic disorder	_____
Date(s) of Birth	_____
Relationship to you	_____
Metabolic Disorder	_____
Volunteer Interests	
Board of Directors	<input type="checkbox"/>
Newsletter	<input type="checkbox"/>
Picnic	<input type="checkbox"/>
Conference	<input type="checkbox"/>
Research	<input type="checkbox"/>

If you would like to make a tax-deductible contribution, please enclose a check payable to MACPAD.

**MACPAD  
P.O. Box 6086  
Lancaster, PA 17607**

## In The Words of Children...



Hi, my name is Krista Byrne. I'm 13 years old, in 7<sup>th</sup> grade and I have Classic PKU. I just wanted to let everyone know that this is not a bad thing but it's like being a vegetarian. I travel all the time with my family for at the most 3 weeks at one time (we went to Alaska and California). We eat out a lot and there is always something on a menu that I can eat like salads, baked potatoes, rice, french fries and vegetables.

My friends all know that I can't eat many of the same things as them but that's cool with them. Most of the kids in 7<sup>th</sup> grade (250) also know that I can't eat certain foods. When we have a special party at school (which as you get older is less often) I just eat chips or popcorn. I have never asked to have special food for lunch at school and thank heavens neither has my mom! Most of the kids pack their lunch anyway – Cafeteria food being what it is, it stinks. I usually take a cheese sandwich (which looks better than when I was on a Ketchup sandwich spree), and add in fruit or applesauce, Gushers or Butterscotch Krimpets (favorite).

My parents never make me feel any different growing up than anyone else. I play sports and my favorite is field hockey. My favorite subjects are Math and Social Studies. I tell people that PKU is not who I am but only a small part of me.

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### Directions to August 4, 2001 picnic

Weavers Farm is located in near Denver, PA in Lancaster County on Route 897 (locally known as Dry Tavern Road). From Exit 21 on the Pennsylvania Turnpike (I-76) follow the exit road to Route 272. Turn right (North) onto Route 272 and follow it approximately 1.5 miles to Route 897. Turn right onto Route 897 and follow it about 3 miles to the Weaver Farm, which is on the right. If you get to Fivepointville, you have gone too far.

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### Interest In Support Groups?

MACPAD has been asked to review the possibility of forming local support groups for mothers of young children and one for grandmothers of children with metabolic disorders. If anyone is interested in either type support group, please email [Griffith@pkumac.org](mailto:Griffith@pkumac.org). with your particular interest and location.



Address: P.O. Box 6086  
Lancaster PA 17607  
Phone: 610-983-9369  
Email: [Info@pkumac.org](mailto:Info@pkumac.org)  
Website: [www.pkumac.org](http://www.pkumac.org)

### **Newsletter Contributors**

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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**

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Ken Barton

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Sharon Johnstone

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Linda Tonyes

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## **Connections**

**MACPAD**  
**PO Box 6086**  
**Lancaster, PA 17607**