

## FIRST ANNUAL PKU WALK - A MAJOR SUCCESS!!

On Saturday, May 4, 2002, over 300 people gathered in Washington Lake Park in Sewell, NJ to begin a day of fun with family and friends and to donate money to PKU research. With a spectacular sunny day, everyone enjoyed the free fruit and water, low protein cooking demonstrations by Diane Sullivan, clowns, face painting, craft tables and much more!



Co chair Debbie Gilliano with MACPAD treasurer Bob Johnstone

Enclosing a "Request to receive funds from the MACPAD Research Fund" with this newsletter. The board is willing to review any research currently being done. If you know of anyone doing research into metabolic disorders, please forward this form to them and notify MACPAD of their name and address. The board welcomes any and all suggestions.



New and old friends at the "PKU Walk"

Co-chairs Debbie Gilliano, Janice Paterno and Desiree Spinney, their families and friends organized a memorable event. Everyone who walked received a free T-shirt and wore them proudly! Thanks to Debbie, Janice and Desiree for their hard work and huge success! At the end of the day, Debbie announced that the walk had raised over \$24,000.00! ALL of the net income will go directly to research of metabolic disorders. To everyone who attended the event, we thank you! Please mark your calendars- the next "PKU Walk" will be May 3, 2003!

Now the Board of Directors will begin the difficult task of deciding where the money can be best utilized. We are



Co chair Janice Paterno and daughter Franki



## THANK YOU!

Dear Friends and Family,

What a pleasure it is for us to write this note. Our 1st annual PKU Walk-A-Thon was a huge success! We have many people to thank who assisted us in this endeavor. We are so grateful for MACPAD's assistance in our Walk-A-Thon. Without their assistance and expertise it would not have been possible. Although the planning required for such an event was extensive the experience we gained was invaluable and the friends we made priceless. It was so rewarding to see everyone come together so willing to lend a hand to the many tasks required to organize this event. Not only was the event a fundraising success, but a community success as well. During the Walk-A-Thon many new friendships were made while others grew stronger. We think this event is just the beginning of many more events for our PKU families and community.

We would like to pass along our sincere gratitude to everyone who took part in this event. We look forward to and eagerly anticipate our 2nd Annual Walk-A-Thon, which we believe, is destined to be an even larger success!

Wishing you and your families all the best  
Janice Paterno  
Debbie Gilliano  
Desiree Spinney



Sarah Foster enjoying the "Walk"

## CONFERENCE 2002- "DIET FOR LIFE"

Friday, August 2, 2002

Our second conference will be held Friday, August 2, 2002 at the Lantern Lodge in Myerstown, PA. Please note that free babysitting will be available on a first come, first served basis during the seminars, so register early to reserve a space.

Registration fees are \$35.00 per household plus \$5.00 per non-PKU individual attending the banquet. MACPAD and the low protein food suppliers are providing a free dinner for those with PKU or other metabolic disorders.

Following is a preliminary schedule of events and speakers:

9:00- ongoing **Vendors exhibits**

9:30-10:30 **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.

10:30-10:45 break

10:45-11:45 – **Small Group Discussions**

**Sports/Social Events and PKU-** Ken Barton

**Feeding a Toddler-** Laurie Graver

**Pocket Phe Book" Workshop-** Anne Starr

11:45-1:30 Lunch on your own

1:30-2:30 "**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.

2:30-3:00- Break

3:00-4:00 **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.

4:00-5:00 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.

A complete agenda and registration form, along with a picnic registration will be mailed around June 15. Watch your mail because we will also be including the tickets for the quilt raffle. You may also register by using the form included with this newsletter.



## **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. Anyone wishing to assist with games, etc., please email [CarolBarton.cabbi@dejazzd.com](mailto:CarolBarton.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



Cambrooke Foods has been busy lately working to bring more delicious low protein foods to your family's table.

Those of you with a sweet tooth will love our new smooth and delicious chocolate Cha Cha's. Some of our other new products include Focaccia bread sticks (Italian herb, Barbeque, and Onion and Dill flavors) and Tuscan pizza crusts. MixQuick, a delicious just-add-water, multi-purpose mix for pancakes, waffles, tempura, biscuits and more and an All Purpose Baking Mix are available too. (See our web site for recipe ideas.) Macaroni and Cheese, Shake 'N' Cheeze, a shaker style premium cheese blend, and Cream Cheese -- plain, wild berry and garlic and herb have been added to our line of delicious cheese products.

Several variety packs are available for purchase including Cameron's Variety Pack, which features favorites like Artisan Bread, Plain Bagels, American cheese, French Toast Energy Bars and Orzo. The bagel variety pack offers all your favorites and is a perfect "go with" for the new cream cheese sample pack. More convenient 2-pound packages of shredded cheddar and mozzarella are now available too.

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.

Our friendly staff is working to make the ordering process easier. You can order 24/7 through our call center, toll-free at (866) 4 LOW PRO/ (866) 456-9776, or over our website at [www.cambrookefoods.com](http://www.cambrookefoods.com). If this is not convenient for you, you can mail or fax your orders to us.

## THE RIGHTS OF STUDENTS WITH PHYSICAL OR HEALTH IMPAIRMENTS WHO DO NOT NEED SPECIAL EDUCATION.

By Karen Blackbird, RD,MS

Some children with disabilities may need special accommodations in school, and yet not need formal "special education." These children can include those with epilepsy, asthma, diabetes, muscular dystrophy or other health or physical impairments. These children have rights under a federal law known as "Section 504 of the Rehabilitation Act of 1973," and state regulations known as "Chapter 15."

**1. What rights does my child have under Section 504 and Chapter 15?** Under most circumstances, the school district must provide the modifications, accommodations and services that a child with a health or other disability needs to participate in and obtain the benefits of the school program. The district must make sure that the child has **equal access** to all school programs and activities, including extra-curricular clubs or programs, assemblies, lunch and field trips.

For example, a district might be required to make changes in a child's schedule to take account of a health need, dispense medication that the child needs during the school day, allow a child who uses a wheelchair to use the staff elevator, provide a desk or other equipment or material that is modified for the child's use, or provide assistance to the child for toileting or for traveling around the school building.

**2. How do I get the services my child needs?** If you believe that your child needs this type of help to participate fully in school, you must *write* to your school district. In your letter, explain the type of assistance you believe is needed. If you have evaluations, records or prescriptions from a specialist that you are willing to share, you should include copies with your request.

The school district must respond to you in writing within 25 school days. If the district agrees that the child needs the services you've requested, you and the district then develop a written, "service agreement," which must state the services that will be provided. If the school district believes that it needs more information to decide whether to provide the requested services, it can ask you for additional information, and for permission to evaluate your child further.

**3. What if the school district and I don't agree on the type or amount of services needed?** You can use any or all of these steps:

You can request an *informal conference* with district officials by sending a written request to the principal or superintendent. Within 10 days of receiving your request, the district must hold an informal conference to try to resolve the disagreement.

If the problems are not working out at the informal conference, you can request a *formal "due process"* hearing by sending a written request to your superintendent. A trained and impartial hearing officer will hear evidence, and resolve the dispute. Hearing officers' decisions can be appealed directly to court if either side is dissatisfied.

If you believe that your child is being *discriminated against*, you can *file a complaint* by sending a letter explaining the situation to the federal *Office for Civil Rights*, which is in charge of enforcing Section 504. OCR's address is: Office of Civil Rights, U.S. Department of Education, Wanamaker Bldg., Suite 515, Philadelphia, PA 19107. However, OCR will not resolve disputes about the type of amount of services your child needs.

You can file a lawsuit under certain circumstances. You should check with an attorney before doing this.

**4. What if the school district doesn't comply with the service agreement, doesn't follow the required procedure or denies my child equal access to a school activity?** In addition to the steps listed in #3 above, you may also send a letter of complaint to the State's Division of Compliance and Planning, 333 Market Street, Harrisburg, PA 17126-0333. The Division will investigate the problem and issue a written report within 60 days, and is required to follow-up to make sure illegal practices are corrected. However, like OCR, the Division will not resolve disputes about the amount or type of services or accommodations that a child needs - that can only be done by a hearing officer, after a formal hearing.

Prepared by the Education Law Center - PA (Revised 11/99)

[www.elc-pa.org/brochures/Chap15.htm](http://www.elc-pa.org/brochures/Chap15.htm)



**Happy Birthday  
To Our MACPAD Friends!**

|                       |          |
|-----------------------|----------|
| Chad Eilers           | June 29  |
| Mary Elizabeth Butler | April 11 |
| Jack Murphy           | April 17 |
| Ariana Spinney        | May 2    |
| Nicole Seymour        | May 6    |
| Logan Persee          | May 28   |
| Cameron Barnes        | May 29   |
| Giovanna Ditro        | June 8   |
| Jakob Arbaugh         | May 22   |
| Shyla Davidson        | April 11 |
| Xavier Kaiserian      | April 11 |
| Claire Zimlinghaus    | May 18   |
| Zachery Wilt          | May 20   |
| Brian Loughlin        | May 31   |
| Veronica Perkins      | June 2   |
| Kyle Stoltzfus        | June 14  |
| Brian Phillips        | May 14   |
| Michael McConnell     | April 8  |
| Debbie Gardecki       | June 21  |
| Deborah Connelly      | April 29 |
| Denise Feeley         | April 1  |
| Sat Guru Singh Kalsa  | April 26 |
| Danielle Whitley      | April 7  |
| Krista Byrne          | April 24 |
| Jock Kane             | April 2  |
| Jessica Smith         | May 28   |
| Donnita Fox           | April 14 |
| Danielle Barckett     | May 31   |
| Stephanie Krupilis    | June 23  |
| Rebecca Schulze       | June 3   |



**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!

**Random Reflections**

Spring is a time for gardening and planting seeds. Parenting is a lot like gardening. We didn't have a choice about the parents that we inherited, but we do have a choice about the kind of parents we will strive to be. We all need to feel good about ourselves, and parents have the power to nourish or damage a child's image of itself. Children born into this world with special needs need to be taught to appreciate their "uniqueness" and know that we ALL are unique in different ways.

Parents should desire to be "planting and nurturing" seeds of core values. The names of a few of these "seed" are faith, self-discipline, patience, perseverance, honesty, discipline, kindness & compassion, generosity, courage, responsibility and a work ethic. The planting of these "seeds" by parents, as well as others that assist in the raising of your son or daughter will empower him or her through the orderly transfer of control and responsibility as contributing adults to society.

Tutoring in our elementary school weekly, I am reminded more keenly of the opportunity we all have daily to influence children. It is a responsibility that we should all embrace and thank God, the Master Gardener of our life, for entrusting these "sprouts" to us. Our children are our future and it is our responsibility to be the best role models and mentors that we can be to them.

As I reflect on our adult sons, I am reminded clearly of various circumstances and individuals that shaped and molded them. It is an awesome, and oh so rewarding experience, to have been selected to be their Mother! They continue to surprise and amaze me as we watch and listen as those "little seeds" planted during their "growing years" continue to sprout upward in their garden of life experiences.

Our children are our legacy and a blessing!

Cindy Hoover

**New Column**

Beginning with this edition, on page 8 & 9, we will be featuring the officers and Board of Directors of MACPAD. This time you'll read about the Co Founders and how the organization was born. Future editions will feature the remaining officers and Board members.

## Grandmas Corner



**Grandma, I am looking for some ideas for summer treats when my grandchildren come to visit. Can you help me?**

Answer:

There are many very easy treats you can make for summer. Having PKU does not stop a child from have frozen desserts. My first suggestion is to buy an electric ice cream maker. I bought myself a reconditioned Cuisinart ice cream maker from Amazon.com for only \$29.00. It works just great. I had previously bought my daughter one (not-reconditioned) for \$59.00.

The easiest recipe I use is for Popsicles. I just use the Tupperware Popsicles molds and chill them with any of the non-dairy flavored creamers. They are low in phe and delicious as well. Rebecca and Stephen especially enjoy the chocolate Popsicles, but any flavor works well.

Another easy recipe is for yogurt. Rebekah Z. posted this recipe on the list serve from TN. Thank you Rebekah. It may be served as yogurt or put into Popsicle molds and frozen. They are very good.

Here is Rebekah's recipe:

|                                      |   |
|--------------------------------------|---|
| 10 oz pkg frozen sliced strawberries | 1 small pkg vanilla instant pudding mix |
| 1 Cup non-dairy Cool Whip            | 2 Tablespoons Sugar                     |
| 1/2 Cup non-dairy creamer            | 1/2 teaspoon lemon juice                |

Combine all ingredients and chill for several hours.

There are many variations using different fruits and even different flavored puddings. Rebekah also made the strawberry using the cheesecake flavored pudding mix. I have tried both and they are both delicious. Using Coffee mate for the non-dairy creamer, Rebekah says the recipe contains 96 phes for the entire recipe.

The other summer treat (but definitely not limited to summer) is any of the ice cream recipes from Virginia Schuett's cookbook. Use the basic vanilla recipe on page 453 of her cookbook and then vary it for different flavors.

Recipe for Vanilla Ice Cream

|   |                                    |
|---|------------------------------------|
| 2 Cups Rich's Coffee Rich                     | 2 to 3 teaspoons Vanilla Flavoring |
| 2 8 oz cartons liquid Rich's Richwhip Topping | 1/8 teaspoon Salt                  |
| 3/4 Cup Granulated Sugar                      | 4 drops yellow food coloring       |

Mix all ingredients in an ice cream freezer. Stir briefly until sugar dissolves. Freeze according to manufacturers directions. For chocolate ice cream, add 1/2 Cup Hershey's Chocolate Syrup. Vanilla has 88 phes for the entire recipe and chocolate has 255 phes. The recipe makes 6 cups of ice cream.

I have also added a mashed ripe banana and substituted banana flavoring in place of the vanilla to make a delicious banana ice cream.

Hope these recipe help and have a wonderful summer!!

Grandma



Uncle Henry's Pretzel Bakery  
P O Box 219 Bowmansville, PA 17507  
1-800-683-8375      www.unclehenry.com  
email - pretzels@ptd.net

*Thanks to all who visited us at the walk-a-thon. Be sure to stop by our table at the conference coming up August 2.*

**Special Note: Our low protein pretzel recipe has changed slightly causing a lower phe...phe is now 5 mg and leucine is 8 mg per 28 grams of pretzel.**

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

Visit our website at  
[Http://dietaryshoppe.com](http://dietaryshoppe.com)

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LOW PROTEIN  
SHOPPING!!!**



We are pleased to offer our *PhenylAde*® Amino Acid Blend in convenient, one-serving pouches. Each serving provides 10 grams of phenylalanine-free protein equivalent with no carbohydrate or fat. Designed to add flexibility in dietary management, the powder mixes easily into ready-to-eat foods and beverages such as applesauce, ketchup, fruit spreads, low protein puddings and juices--it can even be used to fortify PKU formula with extra protein without changing the flavor or volume. The product is ideal for pregnant women, children, teens and adults. A vitamin and mineral supplement may need to be added.

Our MTE Amino Acid Blend offers the same benefits as Amino Acid Blend with the addition of 6 minerals that are typically lacking in PKU diets.

Ask your nutritionist how these products can be used to add variety to your diet.

For further information, visit [www.medicalfood.com](http://www.medicalfood.com) or call 800-605-0410. Before making any changes in your diet plan, please consult with your metabolic professional.

## Meet the Founder and President of MACPAD



My name is Judy Griffith and I am currently the President of MACPAD. My sister and I started the organization in May 1998 because we wanted to do something to connect families dealing with metabolic disorders.

I have three children and have been married to my husband, Mike, for 8 years. Our oldest son, Nicholas, who is 6, does not have PKU. Our middle and youngest sons Charles and Robert both have PKU. Charley is almost 5 and Bobby is 1 ½. When Charley was born, I was ambivalent about having another child. Nick and I were very close and it was difficult for me to adjust to the change of having another child. When Charley was 7 days old, I was out walking for the first time with the boys, and I got a message on my answering machine from the Pediatrician's office saying that Charley's PKU test had come back positive and that we needed to bring him in immediately for a follow-up test. I called the Dr.'s office right away, but got a message that they were closed for lunch. I started looking up information about PKU and at that time could not find any hopeful information. I was devastated, but it really made me bond with him because I felt that he really needed me to take care of him.

After Charley had his follow-up test, we waited 2 ½ days to find out that he did indeed have PKU. On Friday July 31, 1997, we went to Hershey to meet with Dr. Berlin and our dietitian Karen Blackbird. On Saturday, we went to our first PKU picnic at the Weaver's Farm in Denver, PA. We were still in shock, knew nothing about what to expect, and didn't know if we could handle it. It took 3 or 4 months before I really was able to deal with the news and begin living my life again. But I made it through and became a better person because of it.

I have since had another son with PKU. We did not expect

that Bobby would have PKU because of the 25% odds. However, he does have it and this has turned out to be a blessing also. Bobby is a very loving and happy child and we couldn't love him more than we do. Bobby's PKU has also helped Charley tremendously and the two boys have a really special relationship. Charley helps Bobby understand what he can and cannot have. When Charley is not allowed to have something we remind him that Bobby cannot have it either (or sometimes he asks) and then he seems to feel so much better that he is not the only one. Sometimes we find the two of them sitting on the couch together holding hands and drinking their Periflex. The boys are very close and I suspect they will be for their entire lives because of this bond.

It was originally my sister's' idea to create a support group for our area. One of my reasons for wanting to create MACPAD was that I believe that my children should grow up knowing other kids with PKU. An organization like MACPAD can help people make friends with other families dealing with metabolic disorders so that there can be sharing and understanding that cannot come from families who do not have these issues. Only another family dealing with PKU can really understand the difficulties inherent in the daily requirements. I am involved in the MACPAD Central Pennsylvania PKU Support Group where I have made some wonderful friends for myself and for my son Charley. He still talks about his friend Shane who has PKU and asks questions to confirm that Shane really eats the same foods.

In addition to MACPAD and my family, I am working part-time for a healthcare provider network as a compliance attorney. My job involves going to the office 2 days a week and working at home a few hours, though the hours vary depending on what needs to get done. I am working on starting my own business in my spare time. I also volunteer two mornings a week at Nick's Kindergarten class and teach a 2-year-old Sunday school class at my church. I enjoy biking, reading, gardening, cross stitch and mostly spending time with my husband and boys. We have two dogs and a home in Lancaster County.

I find that our biggest struggle with the low protein diet is finding a variety of things that the boys like to eat and preparing our daily meals. The time involved in preparing food for the diet is sometimes overwhelming to me with my already busy schedule. However, I wouldn't trade my boys for anything. My experience has not only been challenging but has changed my life in so many positive ways.



**Meet the Co-Founder and MACPAD Board member:**



My name is Laura Assayag. My husband Amram (Ami) and I have a daughter Kyla who is 18 months old. She does not have PKU.

I went to college at Quinnipiac University in Hamden, Ct where I got my nursing degree. I moved to Pennsylvania about 15 years ago and got my Bachelor's in Nursing at Immaculata College. I have been a Registered Nurse for 16 years. I have worked as Nurse Manager for a home care hospice visiting nurse association, as a Director of Nursing for a long-term care facility and for a short time for an international medical software company. I now work occasionally and concentrate my time on raising my daughter. I am the volunteer website coordinator for my local MOM's Club chapter. I also coordinate and maintain the MACPAD website.

Ami is from Israel but moved to the US to attend college and decided to stay here after that. He works as a software engineer. We travel to Israel to visit his family 2 or 3 times a year and his family comes here about twice a year. We are raising Kyla to be bilingual so she can communicate with Ami's family – even though they all speak English. We also run a home-based business, Intersoft Design Solutions (<http://www.intersoftdesign.com>). We do custom software development and website design. Our first project was to develop a software program ([www.pkulife.com](http://www.pkulife.com)) to help people with PKU manage their dietary intake of phenylalanine.

When my sisters' child was born in 1997 with PKU, my family and I were very concerned- you always think it won't happen to you. In 1998 my sister and I founded MAPAD to

provide support for families dealing with these types of metabolic disorders because we could not find anyone to help us find the answers and support we were looking for. It was hard to even find anyone else who had a child with PKU or knew anything about PKU. As a nurse I had learned PKU but there was so little information out there. There were small groups across the country but nothing locally, so we decided to fill that void. I have met many PKU individuals and families over the past four years and have been very honored to spend time with all of them.



**You can now order MACPAD items online at [www.PKULife.com](http://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](http://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.



## 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•
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- 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)

## POCKET PHE BOOK

MACPAD has recently begun working on a new project with SHS. We felt that it would help our members to create a small book that contains the items most commonly used in a low protein diet. This book will be a great help to adults just going back on diet because it will give them the information they need without overwhelming them. It will also be helpful to parents of children on low protein diets to use when away from home or traveling, or to keep close by whenever they are preparing meals. It will also be a great book to give to friends, relatives, and caregivers to help them understand what foods those on a low protein diet can eat.

You can help us make this book a reality – while giving input on its contents!! We have enclosed a survey that asks you to list the low protein items most commonly used in your house. The categories shown are just for collection purposes and do not reflect the categories that will be included in the final book. At the MACPAD conference in August, there will be a small group that will get together to work on the book, determine the categories and entries in each category, and decide on other related issues.

Thanks for helping us make this project a reality!

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## Quilt Tickets!

Shortly after this mailing, you will be receiving the expanded conference/picnic information. Inside this envelope will be the raffle tickets for the genuine “Amish” quilt that we raffle each year. This year there will be an additional prize, a second prize- silver earrings! Each ticket is \$1.00 and we will, as usual, send you 10. We ask that those who plan to attend only the picnic, use th raffle tickets as a contribution. So start selling your tickets as soon as s they arrive and return them to MACPAD.

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## Salad Dressing

To make a great salad dressing, use 3 Tbsp. Seedless raspberry jam, ¼ tsp salt, ¼ tsp. pepper 1 Tbps. Vinegar and ½ cup vegetable oil. Microwave jam on high for 15 seconds then add other ingredients, 1 at a time. End with the vegetable oil Add oil slowly, whisking constantly. Refrigerate until ready to serve.

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## Summertime FUN

When the kids get bored this summer, try a couple of these activities. Hold a play or a talent show. If you have old cardboard boxes, the children can paint scenery. Let everyone create his or her own performance!

Design a family monogram. Let everyone participate and draw the family monogram. You could have the design made into a stamp and use it to mark books and toys!

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**Editor’s 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.**

## “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 <b>all</b> 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](mailto:info@pkumac.org)  
Website: [www.pkumac.org](http://www.pkumac.org)

### Newsletter Contributors

Judy Griffith, Carol Barton, Sharon Johnstone, Laura Assayag, Janice Paterno, Deb Gilliano, Karen Blackbird, 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

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