

connections

Spring 2000



A Message From the President

Our first cooking demonstration was a huge success! A big thanks to all the volunteers and attendees who made the day a great experience for everyone. We also thank all the women who spent the afternoon quilting. Anyone who would like to volunteer to help plan the next cooking demonstration please call us at 610-983-9369 or email Info@pkumac.org.

Plans for *Conference 2000*, a half day of speakers, socialization, and fun, are still in the works. We have many families registered already and space is getting limited. The conference will take place the day before our annual member meeting and picnic. Please make your reservations now!

Elections for the Board of Directors will be coming up this summer. If you are interested in volunteering a little bit of your time to help plan the direction and activities of MACPAD, please call us at 610-983-9369 or email Info@pkumac.org. The time commitment can be as much or as little as you desire. We have four Board meetings each year; one is the morning of the annual PKU picnic. We are always looking for people to volunteer for special projects i.e. writing articles for the newsletter, mailing newsletters, helping plan special activities like the cooking demonstrations and conference. Most especially we need your ideas! This is your organization – help us meet your needs! Thanks for your continued support!

Laura Johnstone

Have You Made Your Reservations Yet?

Conference 2000 is less than 2 months away and the reservations are filling up! Families are coming from Ohio, New Jersey, Connecticut, New York, Maryland and Pennsylvania to hear the speakers and meet others affected by metabolic disorders. **Even the Philly Phanatic is coming to the picnic on Saturday!**

August 18 and 19 should be a fun filled learning experience for all. Plans for each event are progressing, as you read in the conference packet you recently received. The speakers are prepared, the panelists are anxious to share their experiences and the suppliers are ready to display their new products. Quilt raffle tickets have been distributed, menus are being reviewed and handouts are being prepared.

We need to hear from you if you plan to attend. The meeting rooms and spaces at the conference hotel are limited in the number of people that can be accommodated. We also want to ensure that food, prizes and products are available for everyone who attends.

Send your blue reservation form today to let us know if you will be at the conference and/or the picnic!! Mail to MACPAD, PO Box 6086, Lancaster, PA 17607 or call 610-983-9369 to receive additional information.

MAPKUF

PKU Camp

The Maryland Alliance of PKU Families, Inc. would like to invite you to our 2000 Family Summer Camp. The camp will take place from Thursday, August 10th through Sunday, August 13th, with a day camp on Saturday, August 11th.

We will once again be at Camp Fairlee Manor in Chestertown Maryland. This is a family camp where parents/siblings/guardians join their PKU family member for a weekend of fun and learning. Activities include: camp fires, swimming, rope climbing, arts & crafts, information sessions, and a huge PKU luau! We have air-conditioned sleeping quarters and meeting rooms. All meals are provided (both PKU and non) so parents get a long weekend where they don't need to worry about food!

Camp costs are significantly subsidized by the MAPKUF, Inc. Full camp is \$60 per person with a maximum of \$240 for an immediate family. Day camp is \$20 per person with a maximum of \$80 for an immediate family. And, as an added bonus this year, the PKU member(s) of each family will be able to come to camp FREE OF CHARGE!!

If you would like to find out more about our camp, you can call Rob Kerr at (410) 795-2091, or email him at RobKerr@erols.com.

Happy Birthday To Our MACPAD Members!!



Donnita Fox	4/14
Debbie Connelly	4/29
Jessica Smith	5/28
Cameron Barnes	5/29
Danielle Barckett	5/31
Melinda Gail Fouse	7/15
Jacob Smith	7/16
Charley Griffith	7/20
Ken Barton, Jr.	7/23

Update on House Bill #854

Pennsylvania House Bill #854, the Low Protein Modified Foods Coverage Act, is currently in the Senate Banking and Insurance Committee. Senator Holl is the chairman of this Committee. The Pennsylvania Health Care Cost Containment Council has completed its report concerning the bill. The Council reviews all bills that affect health care and sends a report to the Senate. The report was unfavorable but, because the bill involves a mandated insurance benefit, we expected that the Council would object. The Senate Banking and Insurance Committee does not have to accept this report. We now need everyone to write and call their Senators and Senator Holl to keep the bill moving through the Senate. It has to be signed into law by December or we will have to

start all over again next year. If you need any more information, feel free to e-mail Jeanne Foster at jimmy@psonline.net

To find the email address for your senator use the following link: <http://www.pasen.gov/members/sendemail.html>

Quilt Raffle Tickets are being distributed

At our 13th Annual PKU picnic on Saturday, August 19, a beautiful handmade queen sized quilt will be raffled off. As those of you who have attended the picnic in the past are aware, the quilt is a work of art. Created by Lancaster county women, who donate their time, each stitch in the quilt is completed with skill and love. If you have received tickets, you may purchase them yourself or sell them to others. We would appreciate you returning the ticket stubs and payment (checks made payable to MACPAD) by August 10, 2000. They may also be brought to the picnic (and entered into the raffle before the drawing). The drawing will take place at 3:00 on August 19th.

MACPAD Gains United Way Eligibility

MACPAD has become eligible to receive contributions through the United Way Donor Choice Programs in Southeastern Pennsylvania (MACPAD has I.D. #12456), Lancaster County Pennsylvania, and Blair County Pennsylvania.

The United Way of Southeastern Pennsylvania has partnership agreements with the United Ways of Atlantic, Burlington, Camden, Gloucester and Cumberland

Counties in New Jersey; and Bucks, Chester, and Delaware Counties in Pennsylvania. MACPAD is eligible to receive contributions from each of these United Ways because of these Partnership Agreements. MACPAD applied for approval from these United Way agencies because some of our members requested us to do this. If you would like us to apply in your area, please contact MACPAD at P. O. Box 6086, Lancaster, PA 17607.

Now We're Cookin': Quick and Easy Recipes for PKU Cooking



SHS North America is offering a new video called, "Now We're Cookin': Quick and Easy Recipes for PKU Cooking". This 54 minute long video presented by low protein chef, Diane Sullivan, offers great tips for PKU cooking and preparation. The video is produced by the University of Connecticut Health Center and the Connecticut Children's Medical Center. Cost per video is \$10.00 (includes shipping). For further information and to order, please call SHS North America at 1-800-365-7354.

In the Words of Children...

This is the first in a series of works written by children about what it is

like to live with a metabolic disorder. If you would like to submit something written by your child, please send it to MACPAD PO Box 6086 Lancaster PA 17607 or email Info@pkumac.org.

The following letter was written a few years ago by Kenneth Barton, Jr for school. Kenneth lives in Lancaster Pennsylvania.

P.K.U.

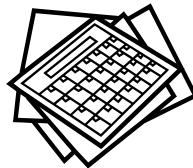
By Kenneth Barton Jr.

What is PKU you ask? I was born with PKU. PKU stands for Phenylketonuria. It is a genetic disorder I had since birth. It is a hard diet to follow. I can't eat eggs, milk, meat, cheese, peanut butter, soy products, and some kinds of beans. I do have to drink a special milk that has vitamins in it. I don't really like it, but it makes me strong. I see a doctor at Hershey Medical Center once a year for a checkup. My mom does my blood work once a month to check my Phenylalanine levels. 2's are great, 8's are not so good and that means I have not been following my diet very well. We have a picnic every year for families and PKU kids. Having PKU is not so bad!

Mead Johnson Looking For Calendar Kids

Mead Johnson Nutritionals is looking for children with a metabolic disorder who are using formulas - Lofenalac, Phenyl-Free, MSUD Diet Powder, UCD 1 and 2, Portagen, and so on. Every year, they put together a calendar that features photos and stories about 12 special kids...children with metabolic disorders who use Mead Johnson formulas. This is their 11th year of publishing the calendar. It is distributed to metabolic clinics and pediatricians offices around the country. Mead

Johnson visits these special families in their homes, and brings a wonderful, professional photographer to take photos of the child. They try to get shots of the child participating in some of his or her favorite activities -- riding a bike, skating, ballet lessons, etc. The kids love it because they are the "star" for the day! And families love having their child featured in the calendar.



Each child has a calendar month - so his or her photos are featured that month, along with a story about the child. This story talks about all of the things that make up the unique personality of the child. The stories are written by Tracy Boeckmann, a writer for Mead Johnson and a mother of three small children. She makes sure they are filled with only wonderful comments, and lots of love and laughs! Many families of newly diagnosed children receive these calendars. Many parents have said that seeing the photos of these normal, healthy children, and reading how these kids are involved in every kind of activity imaginable, has been so encouraging for them. They see for themselves that the only thing different about these kids is their diets.

Mead Johnson is looking for families who might be interested in appearing in the 2002 calendars. It's really easy to do - just send e-mail to TWhyte@aol.com including the child's metabolic disorder, age, and city/state. Also, be sure to include your child's age, what formula he or she is on, where you live, and your e-mail address and phone number. Remember, your

child must be on a Mead Johnson formula to be considered.



Mead Johnson Metabolics has three new educational booklets available.

Family Guide to PKU An Informational Guide to Dietary Management of Individual with PKU. This 23-page booklet includes information about PKU, managing the PKU diet, effects on the family and tips for parents.

Adult PKU: Important Information for You. Discusses how PKU affects you and the PKU diet.

Maternal PKU includes information about how to have a healthy baby and diet ideas.

To get your copy of one or more of these booklets call 800-457-3550 or order online at www.meadjohnson.com/metabolics.

MACPAD Becomes Part of The Special Kids Network

The Mid-Atlantic Connection for PKU and Allied Disorders, Inc. has been accepted into the database of The Special Kids Network, a Pennsylvania Department of Health statewide system to assist families of children with special needs. The Special Kids Network combines information and referral services with community systems to ensure that families are able to obtain the services they need for their children with special needs. There are six regional offices of the Special Kids Network covering all of Pennsylvania. MACPAD is listed with all of them. The Special Kids Network toll free telephone line, 1-800-986-4550, connects callers with a trained telephone counselor in their area who can provide information and referrals to help the caller. The counselor can provide information about local, state and national agencies that can provide help in the following categories: education and training, healthcare products and services, recreation and leisure, social services and counseling, support and advocacy, and therapy.



MACPAD is pleased that we have been accepted into the Special Kids Network. This will help us to further our mission to provide help to individuals and families of individuals with metabolic disorders.

LANCASTER COUNTY COOKING DEMO AND QUILTING BEE

On a quiet afternoon in late April, on a farm in northern Lancaster County, PA, eight Amish women sat around a table in a barn quilting. They were making a quilt that will be auctioned at the annual picnic held in August and sponsored by the Mid-Atlantic Connection for PKU and Allied Disorders, Inc. and the Hershey Medical Center.

At the same time, in the kitchen, Nancy Benedict, a mother of two children with PKU, was demonstrating the technique for baking the perfect loaf of low protein bread. Nancy's recipe uses basic ingredients, with wheat starch as the main ingredient for the bread. The recipe is made by hand, rises in a warmed oven, and is easy to make. It is great for sandwiches because it is very soft, but it is also easy to slice. It can also be used for making low protein hotdog rolls or sandwich rolls.

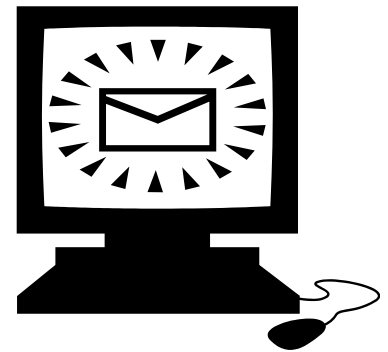
There were approximately 25 people who came to the cooking demonstration. These mothers, grandmothers' aunts, and other friends and relatives of children with PKU came from all over Pennsylvania, Delaware and New Jersey to learn the best techniques and hints for making bread. During the afternoon, we also shared low protein pizzelles, low protein chocolate chip bars, drinks and some great conversation! There were Uncle Henry's pretzels and low protein baking product available, thanks to Brenda Wenger, a mother of two children with MSUD, who purchases items in bulk and has them available for families in the area.

A special thanks to Nancy Benedict, Anna Weaver, Brenda

Wenger, Karen Blackbird and everyone who came to the demonstration and helped to make it a great success!! If you would like a copy of this recipe, please visit our website at www.pkumac.org.

Tyler For Life Foundation announcement

The Tyler For Life Foundation is happy to announce that it is now hosting a discussion group for persons wanting to communicate about newborn screening advocacy. If you are interested in signing up for the discussion group mailing list, please visit our website at www.tylerforlife.com. You can subscribe to the discussion group mailing list at the bottom of the home page.



Please be advised that the Tyler For Life Foundation mailing list (this list) is NOT automatically included in the discussion group list. If you want to participate in the discussion group list, you must subscribe.

Tera Mize, Tyler For Life Foundation, Inc. *Dedicated to Raising the Awareness of Newborn Screening and Related Disorders.* For more information about our efforts, please visit <http://www.tylerforlife.com>

Mead Johnson New Phenyl Free

Mead Johnson Metabolics has recently reformulated Phenyl Free powdered medical food. There are two products intended for children and adults with PKU: 1) Phenyl Free 2 and 2) Phenyl Free 2HP. Phenyl Free 2 contains soy oil (20% of total calories) as the fat source replacing corn oil and coconut oil (15% of total calories) in Phenyl Free. Soy oil supplies essential omega 3 and omega 6 fatty acids. The levels of essential amino acids are increased, as are levels of B vitamins and trace minerals. As an added bonus, the physical characteristics of the new Phenyl Free 2 are improved. A small amount of vanilla flavoring has been added to impart a pleasant odor and taste resulting in a powder that smells like vanilla cake mix. The powder mixes easily and stays in solution without separation as a result of modified

cornstarch. The packaging (6 cans of one pound per case) remains the same. Phenyl Free 2 HP (High Protein) has twice the protein of Phenyl Free or Phenyl Free 2. It was designed for two purposes: 1) pregnant woman with PKU (2) children and adults with PKU desiring significantly less total calories or less total powdered medical food than provided by Phenyl Free or Phenyl Free 2. Phenyl Free 2 HP has all the improvements of Phenyl Free 2. Due to the significantly increased level of essential amino acids (protein) in Phenyl Free 2 HP over and above Phenyl Free or Phenyl Free 2, the taste may be less appealing to some. However, the addition of citrus type flavorings such as Tang complement and improve the taste of Phenyl Free 2 HP. It is suggested that individuals consuming Phenyl Free change to the new product by gradually replacing 10-30 grams (1-2 Tablespoons) of the older version with the same amount of the newer

version over time. Your dietitian will advise individuals on the transition. The Pennsylvania State Department of Health plans to add Phenyl Free 2 and Phenyl Free 2 HP to the current medical foods provided by the state. The products are also approved for those individuals receiving WIC (Women, Infants, & Children) benefits. Since the State PKU Program orders the yearly bulk of our PKU medical foods in August/September, we can anticipate the new products to arrive in late Fall 2000. Some quantities of Phenyl Free will still be ordered to assist with the transition. However, Mead Johnson plans to manufacture the older version of Phenyl Free until Summer 2001. The State Programs of New Jersey and Delaware are also making arrangements for the new products.

Mead Johnson's web site:
www.meadjohnson.com/metabolics.

To join MACPAD, get involved, or show your support, please send this form to : MACPAD PO Box 6086 Lancaster PA 17607

Name _____

Address _____

Telephone _____

E-Mail _____

Name of Person with Metabolic Disorder: _____

Metabolic Disorder: _____

Metabolic Clinic Affiliation: _____

I would like to:

- Become a member of MACPAD (annual fee: \$30 per family/\$50 per business)
- Renew membership (\$10 annual family renewal, \$50 per business)
- Purchase a cookbook (\$14.00; PA residents add \$.85 sales tax; outside U.S. call for shipping charge)
- Purchase a MACPAD T-shirt (\$8.00 for MACPAD members; \$10.00 for non-MACPAD members).
- Volunteer to serve on the Board of Directors
- Serve as a contact for parents of children newly diagnosed with a metabolic disorder
- Make a tax deductible contribution to MACPAD in the amount of \$ _____
- Receive more information about the Genuardi's Community Cash Back Program and how it benefits MACPAD.
- I am a parent of a newborn who was recently diagnosed with a metabolic disorder and would like to hear from parents of a child with this disorder.
- Receive more information about Conference 2000.



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Website: www.pkumac.org

Newsletter Contributors

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

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MACPAD
PO Box 6086
Lancaster, PA 17607

Please help MACPAD enrich the lives of those affected by metabolic disorders by making a tax-deductible contribution.
Our UNITED WAY SPECIFIC CARE code number for Southeastern Pennsylvania is 12456.