

MACPAD

The Mid-Atlantic Connection



for PKU and Allied Disorders, Inc.

MESSAGE FROM THE

August 7, 1999 was a very busy day for MACPAD members! Not only did we have our most successful annual PKU picnic ever; we also had our second annual member meeting which was highlighted by the election of new members to our Board of Directors. In addition, we discussed many ideas for activities and fundraisers for the upcoming year. We are planning a conference that will be held in conjunction with the picnic next year. Other ideas that we will begin working on are cooking demonstrations and new parent support. We are in the midst of our annual membership renewal drive. All MACPAD members who need to renew their membership should have received the renewal form and information. Your membership has enabled us to get this organization off to a great start and now we need your continued support. There are various levels of support you can provide:

1. **Make a tax deductible contribution** that will help us cover operating expenses and plan interesting activities. We will accept donations in any amount at any time.

2. **Support fundraising activities** such as the cookbook and T-shirt sales. Our cookbook includes recipes created by families, along with helpful menu planning hints for parents with young children who have PKU. By buying a T-shirt you can help advertise PKU and our organization.

3. **Become a member of the organization.** Members of MACPAD receive a variety of benefits most important of which is the ability to support your local PKU organization. You will also receive a member ID card, voting privileges on all issues on which the Board requests guidance, including voting for the Board members, and discounts at events and on purchases.

4. **Be a parent contact** for parents dealing with a new diagnosis of a metabolic disorder or who would like extra support. This project is just beginning and with your help, we can create a support network that will encourage families to share their experiences with families struggling with a new diagnosis or with maintaining or re-establishing dietary control.

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MACPAD T-SHIRTS ARE HERE!

We now have t-shirts available. They are light gray with the MACPAD logo appearing on the front. The logo is dark blue and red, just like it appears on the cookbook. The t-shirts debuted at the PKU picnic held on August 7th, and they were a hit!! We have children's sizes in small and medium, and adult sizes in small, medium, large and x-large. If you need a large size for a child, it is recommended that you order an adult small. The t-shirt supplier said they are almost identical. We still have some shirts left after the picnic, but they are going fast. So, don't delay - order your's today! The cost is \$ 8.00 for MACPAD members and \$10.00 for non- members. So, if you're not a member, why not consider joining today?? You can see a benefit immediately in t-shirt savings!

If we do not have your size, we can order more. It may take a few weeks until we have a full order, but we will try to be as accommodating as possible. Get your MACPAD t-shirt before it's too late and show off OUR group. **To order, contact MACPAD at 610-983-9369 or Info@pkumac.org.**

1999 ANNUAL

At our annual member meeting we elected two members to the Board of Directors. **Ken Barton**, of Lancaster, Pennsylvania, was re-elected for a two-year term. Ken is the father of Kenny, Jr. who is 7 and has PKU. **Pam Barkett**, of Totowa, New Jersey, is a new member of MACPAD and our newest board member. Pam's four year old daughter, Danielle has Tyrosinemia type 1. Pam and her family are very active in NORD (National Organization for Rare Diseases). We are very pleased to announce that **Linda Tonyes**, dietitian at the PKU clinic at St. Christopher's Hospital for Children in Philadelphia, has been appointed an honorary member of the Board of Directors. We are sad to report the resignations of three of our Board members: Sharon Johnstone, Sherry Allwein, and Micheal Griffith. Thanks to Sharon, Sherry and Micheal for helping us get the organization off the ground. We couldn't have done it without you!

The new Board of Directors will convene in January 2000 when we will have elections for the open positions of Vice President, Activities and Fundraising Chairs and continue with our plans for the new millennium.

PKU ADULTS TO WRITE BOOK- NEED YOUR HELP!

PKU adults, Sarah Foster and Tracy Beck are in the beginning stages of writing a book about what it is like to live with PKU. Because they realize that their experiences of living with PKU aren't the only ones, they are looking to get in contact with as many on and off diet PKU adults and young adults as possible to fill out a questionnaire to help provide text for the book. If you are interested in completing their questionnaire please contact Sarah and Tracy by writing, calling, or emailing them at:

Sarah Foster
81 Strathmore Rd., Apt. 4
Brighton, MA 02135
(617) 738-0282
PKUADULT@aol.com



NEW

In addition to the fabulous low protein cheeses offered by Ener-G Foods, we now have another product to choose from. Whitehall Specialties Cheese Co. in Wisconsin manufactures imitation low protein cheeses that can be found in retail stores throughout the Mid Atlantic region. The cheese has been purchased at Spain's, Dollar Express and Dollarland.

Whitehall's pasteurized, processed imitation sandwich slices are individually wrapped weighing 19 gm each. There are four flavors: plain, jalapeno, pizza, and suizo (swiss). The

most commonly found flavor is the plain. The cheese is sold both under the Whitehall label (as Whitehall Specialties Pasteurized Processed Sandwich Slices), and under many other brand names as well. Sometimes you can identify the cheese, even if it has a different brand on it, by noting in fine print that it is manufactured or distributed by Whitehall Specialties, Whitehall, Wisconsin. Whitehall Specialties has provided the following nutritional information for one 19 gm slice of the individually packaged cheese:

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**MACPAD COOKBOOK-
A RESOUNDING SUCCESS!**

CREATIVE FAMILY COOKING: Recipes & Menu Planning Ideas for PKU made its debut this summer. MACPAD's first cookbook and fund raiser contains over 150 recipes gathered from individuals and families from over all over the United States, Canada and Iceland. The menu planning has received rave reviews. As of July 31, we have sold 221 cookbooks to individuals in 42 states and have a profit of over \$1000.! We have received orders from universities, hospitals, foundations and related health services. The support from MACPAD members has been wonderful. Thanks to all of you who submitted recipes and purchased the cookbook! **To order the cookbook**, please forward a check for \$14.00 (PA residents need to send \$14.84) to MACPAD Cookbook , P.O. Box 6086, Lancaster,PA 17607.

BETTER BEST WHITE BREAD

From Nancy Benedict, Lititz, PA

400 g **Wheat Starch**
 2 tsp **Methylcellulose** (available from Ener-G Foods)
 45 g **Metamucil**
 1 tsp **Salt**
 1 Tbl + 1 tsp **Sugar**
 7 g **Yeast**
 415 g **Water**
 ½ tsp **Dark molasses**

Mix dry ingredients together with a wire whisk. Mix molasses with warm water, add to dry ingredients (the molasses is for coloring and adds no taste). Scrape dough from the edges of bowl and cover with plastic wrap. Let rise for 30 minutes in an oven that has been warmed at 350 degrees for 1 minute. Scrape out on lightly starched board and knead for three minutes adding a little wheat starch as necessary. Place in regular size loaf pan that has been well greased with butter and let rise about 45 minutes in the oven that has again been warmed. Let the loaf rise only one inch above the top of the pan; this recipe really rises in the oven. Bake at 375 degrees for 15 minutes and brush the top with butter. Let bake another 35 minutes and turn out on a wire rack. Allow to cool slightly, then, while still warm, place in a sealed ziplock bag. This will produce nice soft bread. Cut when cool and somewhat firm.

Approximately 13 mg. phe for each of 15 slices (190 mg. phe/recipe)

BETTER BURGER BUNS AND SUB ROLLS After first rising scrape out on lightly starched board and knead for three minutes adding a little wheat starch as necessary. Shape into 12 burger buns or 8 sub rolls (or as many as you like depending on the size you need). Let rise about 30-45 minutes until doubled in size. Bake at 375 degrees for 30 minutes. Brush with butter. Place in sealed zip-lock bag while still warm to make a nice soft roll. Cut when thoroughly cool.

NEXT ISSUE: HOMESTYLE BREAD

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 5. **Volunteer to serve on one of the three committees** that direct the activities of the organization- Fundraising, Activities and Information; as these committees begin to organize, the Chairs will plan meetings or correspond with members over the Internet or by telephone. There is no requirement to attend committee meetings, but if you volunteer, you will be asked to write articles, organize activities, plan events or help with other projects. Most of this work can be done from your home.

6. **Volunteer to be a member of the Board of Directors.** Board membership requires MACPAD membership and attendance at 4 meetings every year either in person or via telephone. The summer meeting is usually held the day of the picnic. If you are elected or appointed to a position on the Board, you will be asked to contribute ideas for helping the families dealing with PKU or another metabolic disorder, to vocalize concerns and problems encountered by families dealing with PKU or

another metabolic disorder, and to help find and carry out events, activities and solutions. We would like you to renew your membership and continue to support MACPAD. **Your membership fee and/or donation are a tax deductible charitable contribution.** If you are a member and have not received this information please let us know. We can be reached at our new phone number 610-983-9369 or at Info@pkumac.org. If you are not a member, please consider supporting us. We are working toward finding ways to make living with metabolic disorders easier and to create a community among our families. Your money and/or time will be used for achieving these goals. As the organization grows and we receive more and more support from individuals and families in the mid-Atlantic region and across the country, we will be able to initiate new programs, plan more events, provide more support and bring you closer to other families dealing with metabolic disorders.

Thanks for your continued support!
Laura Johnstone

Join us in wishing a
HAPPY BIRTHDAY
 to our members with
PKU!!!!!!!!!!



8/4 - **Shane Shuler**
 8/8 - **Allison Zimmerman**
 8/16- **Eric Johnson**
 8/19- **Deidra Kline**
 8/23- **Amy Shuler**
 9/4 - **Steven Droogan**
 9/28- **Jack Robertson**

And a belated happy 10th birthday to
Rebecca Lehman
 (3/12)

And a special welcome/birthday wish for our youngest PKU child- **Jessica Schlotter** born 8/1/99

**MACPAD/HERSHEY PKU CLINIC
COSPONSOR 2ND ANNUAL
PICNIC IN PENNSYLVANIA**

On August 7, 1999, the Mid-Atlantic Connection for PKU and Allied Disorders, Inc. co-sponsored its second annual picnic and fun filled afternoon. Traditionally, this picnic has been sponsored by the Hershey Medical Center PKU Clinic and has been organized by Karen Blackbird. MACPAD began working with the clinic and Karen, an honorary MACPAD Board of Directors member, in 1998 and will continue to co- sponsor the event.

This year's picnic began at 12:00 noon, with PKU families (along with some MSUD families) arriving at the Weaver farm in Denver, PA. There were 140 people present from Pennsylvania, New Jersey, Delaware and Maryland. A full low protein buffet was served at 1:00 and Stan the Magic Man performed shortly after lunch. In the afternoon, there was a petting zoo, pony rides and hayrides. Everyone with PKU or MSUD received a slice of low protein Whitehall Specialties cheese and a low protein peanut butter cup.

The Quilt raffle was won by Herbe Charles of Lancaster, PA. Brenda Leiphart of Dallastown, PA won a donut maker and Peg Lunt of Delaware won a bag of goodies from Applied Nutrition.

The day ended with the distribution of a bag of low protein foods donated by Applied Nutrition, a bag of toys, games and treats for the kids, a low protein cake mix and a copy of a delicious low protein bread recipe contributed by Nancy Benedict of Lititz, PA. The recipe is included in this newsletter.

We would like to thank Mead Johnson, SHS, Menu Direct, Applied Nutrition and Ener-G Foods for their generous contributions toward the low protein buffet, the goodie bags and support for picnic costs. Also, thank you to the Weavers for allowing us to use their farm again, and to Karen Blackbird, and Sherry Allwein for organizing the event and making it such a great success.

cheese, from page 2

Phenylalanine (mg) 29
Protein (gm) 0.7
Calories (Kcal) 57
Tyrosine (mg) 32
Methionine (mg) 17
Valine (mg) 38
Leucine (mg) 52
Isoleucine (mg) 33
Threonine (mg) 23

Virginia Schuett made the following comments on the Nutrient Values of the Whitehall Cheeses*

The nutrient values are calculated based on the ingredients used and the known content of those ingredients. The cheese was NOT analyzed by a laboratory (unlike the cheeses distributed by Ener-G Foods), which may give slightly different results. However, I have a fair degree of confidence in these numbers, after discussing them thoroughly with someone in the laboratory at the Whitehall company. Since the only source of protein in the cheese is casein and/or caseinate and whey, and since the company now has very good amino acid information on these products from their supplier, I think the numbers are adequate for our use. (I suggest you consider adding a few extra mg of phe if you want to be super conservative and plan to use the cheese as a regular part of a very restricted diet.)

*reprinted from pku listserve

MACPAD HAS NEW ADDRESS AND PHONE NUMBER

Address: PO Box 6086
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Email: Info@pkumac.org
Website: www.pkumac.org

Newsletter Contributors

Ken Barton, Judy Griffith,
Sharon Johnstone, Jodi Schatz, Laura Johnstone
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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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SECRETARY  
JUDY GRIFFITH  
TREASURER  
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**MACPAD**

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