

connections

Winter 2000



A MESSAGE FROM THE PRESIDENT

We are about to embark on our most ambitious year so far! We have announced plans for *Conference 2000*, a half day of speakers, socialization, and fun! The conference will take place the day before our annual member meeting and picnic. (See related article).

In addition to the conference, we have also planned two cooking demonstrations. The Philadelphia area cooking demonstration will be held at the Restaurant School. The Lancaster area cooking demonstration will be held in conjunction with a quilting bee. Volunteers will be making the quilt that we will raffle off at the picnic. (See related article).

January 1, 2000 we unveiled our newly redesigned website, thanks to Intersoft Design Solutions. If you haven't already, check it out - www.pkumac.org.

Also this year, we have new fundraising projects in place. We are part of Genuardi's Community Cash Back Program. In addition, we have become designated to participate in the

United Way Donor Choice/Specific Care Program. Your donation allows us to sponsor activities such as the cooking demonstration and Conference 2000.

Thanks for your continued support!

save your GENUARDI'S receipts!!

MACPAD is a participant in Genuardi's Cash Back Program. This program involves virtually no work for our members, yet provides cash rebates for MACPAD. MACPAD will use the money raised to print brochures, cover the costs of the annual PKU picnic and sponsor its first annual conference. All you have to do is save your Genuardi's receipts, and send them to MACPAD. Genuardi's will send a rebate check to MACPAD equal to one percent of the total face value of the receipts. Last year Genuardi's gave \$1.3 million in rebates and has given more than \$14 million to non-profit groups since 1976. Please start saving Genuardi's receipts now, and ask your friends to save their tapes for you. Our group can't afford to pass up this unique opportunity. Mail all the tapes you have collected to: **MACPAD, P.O. Box 6086,**

What's Happening?.....

Here's a little information about some activities and events that are planned for this spring and summer around the country and the world relating to PKU and related disorders. Look for updates in future issues of Connections.

The PKU Organization of Illinois is sponsoring a Discovery Day in May and picnics in June and July. The June picnic will be held in the Chicago area and the July picnic will be in Bloomington.

The National Society for Phenylketonuria in the United Kingdom is holding its annual conference in March. This 27th annual conference will be held at the Norbreck Castle Hotel in Blackpool, England.

The New England Connection for PKU and Allied Disorders, Inc. is holding an annual metabolic conference at the Holiday Inn in Taunton, Massachusetts. The conference is for PKU, Homocystinuria and the Organic Acidemias. Speakers include Drs. Harvey Levy and Richard Koch. Dr. Levy will discuss possible national treatment guidelines for PKU and the reduction of false negative newborn screening results. Dr. Randy Eisensmith will present the latest information about gene therapy research. There will be a PKU panel and small group discussions. Formula and food companies will answer questions and show products throughout the day. If you are interested in attending, call the NEC at 508-261-1291 or e-mail Trish Mullaley at pkuconnect@aol.com.

The MSUD Family Support Group is holding Symposium 2000 this year at the Sheraton Ferncroft Resort in Danvers, Massachusetts. It will be held from June 22 to June 24th.

CONFERENCE 2000!

Make your reservations now!

Mark your calendars- August 18 and 19, 2000 will be exciting! MACPAD proudly announces plans for our first conference in Lancaster, Pa.

Here are some of the **highlights** of the events:

Education: We are delighted to have **Dr. Holmes Morton**, founder of The Clinic for Special Children in Strasburg, Pa. as our keynote speaker. Dr. Morton has devoted his career to treating and researching metabolic disorders. In addition, **Dr. Dianne Frazier, PhD, RD** of the University of North Carolina will be discussing her 18-year experience in the dietary treatment of metabolic disorders.

Discussion: We have planned a teen rap session, **PKU for Me and You**. Moderated by PKU adult, **Deborah Connelly**, this will be an informative discussion where teens will answer questions and present their views on living with PKU.

Information: For the younger set, children in grades 1-5, **Karen Blackbird and Linda Toyne** will present **Discovery Day**, where low protein diet principles will be reviewed through games and activities.

Nutrition: All low protein food suppliers have been invited to attend the conference and exhibit

their products, especially the new ones.

Socialization: We have planned a Meet-N-Greet reception which will feature food, beverages and the opportunity to get to know each other and discuss common concerns.

Function: Saturday begins with a MACPAD member meeting and winds up with the **13th annual picnic**, cosponsored by **The Milton S. Hershey Medical Center**. A petting zoo, PKU Bingo and a low protein buffet (for all guests with metabolic disorders) are just some of the special plans. (Options are available for those who will not be enjoying the buffet). Many of you remember the annual quilt raffle and will be anxious to participate. This years quilt will again be handmade!

Here's how to register and/or receive more information.

The registration fee is \$25.00 per MACPAD member household and \$35.00 for non-members, which covers all events. If you plan to attend only the picnic, we request a \$20.00 donation, per household, which can be in the form of raffle tickets.

If you would like more information about any segment of the conference or have specific questions or if you would like to obtain raffle

tickets, please call 610-983-9369 or visit our website www.pkumac.org.

When your blue registration form and payment are received, additional information for registrants will be mailed to you. If you did not receive a conference packet, call 610-983-9369. At the conference, you will receive an additional packet, which will include name badges, door prize tickets, a map to the picnic and much more!

Conference information packets have been mailed to over 240 families. Space at the seminars will be limited, so be sure to reserve your place early! Mail your blue registration form and check, made payable to MACPAD to

MACPAD Conference, PO

**HAPPY BIRTHDAY TO
OUR MACPAD
MEMBERS!!**

Matt Jerrehian 10/4
Gage Fowler 11/3
Brendan Dockery 12/7
Matt Gubenski 12/24
**Francesca Paterno
12/31**
Greg Reynolds 1/27
Daniel Gilbert 2/28

NEW RESOURCE FOR NUTRITIONAL DATA

Scientific Hospital Supplies (SHS) North America and Virginia Schuett are collaborating to make more foods accessible to people with PKU. SHS has funded a PKU Food Data Coordinator, Fran Rohr, to work with Virginia to obtain nutrient information on new foods that appear the most promising for the PKU diet. Fran was the highly respected nutritionist for the PKU clinic at Boston Children's Hospital for many years. She was also a project nutritionist for the Maternal PKU Collaborative Study.

Fran and Virginia have set the following guidelines for gathering data on new foods:

1. The top priority for researching new foods will be for those that state on the label that they contain either zero or 1 gram of protein per serving.
2. In considering which foods to pursue, they will also consider the potential value of the food in the diet and the distribution of the product (ones with a wider distribution nationwide will have a higher priority).
3. They will only consider foods manufactured in the US.

Anyone can request research of a new food by sending an email to the Listserv (PKU-SUPPORT-L@LISTSERV.CC.EMORY.ED

U). In the SUBJECT line of the e-mail, use the heading NEW FOOD DATA REQUEST. For each request, include the following information:

- Exact name of product
- Type of store and which state you found it in.
- Name of manufacturer, city and state, and toll-free telephone number or e-mail address/Web site address.
- Protein per serving (listed on the product label)
- Calories per serving (listed on the product label)
- Serving size in both common measure and weight in grams (listed on the product label)
- Ingredient list, in order that it is given on the product label.

Fran and Virginia will post information about products to the entire Listserv. Thank you Virginia and Fran for this exciting new project!!

PENNSYLVANIA NEWBORN SCREENING UPDATE

Governor Ridge's new budget includes funding for testing for two more metabolic disorders. In addition to PKU, Congenital Hypothyroidism, Maple Syrup Urine Disease and Hemoglobinopathies, the budget now includes money for testing newborns for **Galactosemia** and **Adrenal Hyperplasia**. The Health Department has also agreed to submit approximately 25 other

metabolic disorders to its Newborn Screening Advisory Committee for consideration.

Thank you to those MACPAD members who have spearheaded this effort!

WE STILL HAVE COPIES OF CREATIVE FAMILY COOKING: recipes and menu planning ideas for PKU

Here is a sample of one of our fabulous recipes!

vegetable pot pie

1 sheet (18g) Athens phyllo dough

1/4 cup (20g) fresh broccoli

1/4 cup (28g) fresh carrots

1 Tbsp phe free margerine, melted

1 packet George Washington Golden Broth mix

Preheat oven to 350 degrees. In a small saucepan, steam the cut vegetables in a small amount of water with broth packet added. While vegetables are steaming, cut the phyllo dough into 3 pieces Working quickly, place one piece on a clean surface and brush with margerine. Place second piece on top and brush with margerine. Follow with the last piece of dough and then place layers in a small pot pie tin. Pour in the vegetable mixture and bake 15 minutes.

TOTAL PHE 81 mg

For this and other great recipes, please send a check for \$14.00 (PA residents need to send \$14.84) to MACPAD Cookbook, P.O. Box 6086, Lancaster, PA 17607.

MACPAD

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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**

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CONNECTIONS

**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 is 12456.