

MACPAD

Volume 1, Issue 2

Spring 1999

The Mid-Atlantic Connection

for PKU and Allied Disorders, Inc.

MESSAGE FROM THE PRESIDENT

Can you believe it's been a year? Our first anniversary of incorporation is May 8, 1999. I want to take this opportunity to thank the members of our Board of Directors who have donated their time and energies to getting this organization off the ground. We have come a long way in the last year! Our Board members are:
Sharon Johnstone, Vice President,
Fundraising Chair
Judy Griffith, Secretary
Robert Johnstone, Treasurer
Sherry Allwein, Activities Chair
Jodi Schatz, Information Chair
Ken Barton
Micheal Griffith
Sarah Foster
Karen Blackbird RD, Honorary member
Thanks to all of you who have supported us and helped make this a successful year.

Presently, we have 7 individual and 19 family members representing 22 PKU children and adults with PKU or an allied disorder. Our members represent six states - Pennsylvania, Delaware, Maryland, Connecticut, Missouri and New Jersey. Recently, our Board of Directors decided to expand our membership options to include a business membership. Our first business member is none other than Reflections in Silver - the family owned business that donated the prize for our first membership contest. In addition to our members, we have a mailing list that consists of more than 60 individuals and families from around the world. This enormous amount of support from so many people in a short period of time is overwhelming and confirms how important it is that we as

a community come together to encourage and support each other.

We are planning the 1999 Annual PKU Picnic Sponsored by The Milton S. Hershey Medical Center and MACPAD. The picnic is scheduled for August 7, 1999 from 12pm to 4pm at the Weaver's Farm in Denver, Pennsylvania. For the first time MACPAD t-shirts will be for sale prior to and at the picnic. Keep an eye on the website for more information.

In addition to the picnic, we will be holding our 2nd Annual Member meeting the morning of the picnic from 10am - 12pm. All members and their families (or anyone interested in becoming a member), are invited to attend. We will also be holding re-elections for four positions on our Board of Directors. In the near future all members will be receiving more information about the election and how to nominate yourself or another member. Check your mailbox!

The highlight of our first year is also our first fundraiser. Our first cookbook called **Creative Family Cooking: Recipes & Menu Planning Ideas for PKU** will be ready for sale this June. Advanced copies can be ordered through the website or see the article in this newsletter.

We have made many accomplishments this first year with the help of many people. It is my sincerest wish that the interest and support we have received this year will continue to grow. It has

MEMBERSHIP CONTEST WINNERS!!!!!!!!!!!!!!

Congratulations to Kathy and Mike Gorman of Gibbsboro, New Jersey. Kathy and Mike are the winners of our Membership Contest. Their prize, an original sterling silver pendant with a garnet cabochon, was created by Reflections in Silver.

Reflections in Silver designs are created by Mary Carolyn Walker and her son, Ted Walker. Mary Carolyn has been designing and making jewelry since 1960. Ted joined her in the business in 1990. Reflections in Silver jewelry can be found in nearly 100 shops throughout the United States. Mary Carolyn and Ted show their work at craft shows all over the east coast. Both are juried members of the Pennsylvania Guild of Craftsmen.

Thank you to the Walkers for their generous donation of the Membership Contest prize!

been said that it "takes a village to raise a child", if so our children with PKU, and allied disorders, will be raised with lots of love and support from the PKU community we represent.

Thanks again for your support in this successful first year.

Laura Johnstone

**ANNOUNCING!
12th ANNUAL PKU
PICNIC**

**SATURDAY, August 7, 1999
noon - 4:00pm
At WEAVER'S FARM
DENVER, PA**

BETTER THAN EVER!!!

SCHEDULE OF EVENTS:

12:00 - 1:00 Petting Zoo, Pony Rides, Crafts, PKU Bingo
1:00 - 2:00 Lunch (details below)
2:00 - 2:30 "Stan the Magic Man"
2:30 - 2:45 What's New? (update on foods and formula)
2:45 - 3:00 Raffle Drawing, Awards
3:00 - 4:00 Wagon Rides

To RSVP and Order Raffle Tickets call: MACPAD at (610) 380-8281 by July 24

DONATIONS of \$5-\$20 per family appreciated (or whatever you can afford: it may be in the form of raffle tickets!)

DON'T FORGET YOUR RAFFLE TICKETS!

Lunch Details:

A variety of low protein foods (mushroom & broccoli burgers, low-protein rolls, potato salad, fruit and veggie platters and desserts) will be provided, along with iced tea and lemonade. If you feel you or your children who do not have PKU will need some additional foods, please feel free to bring a cooler along with other foods for your family.

Pennsylvania Insurance Legislation

Thanks to the hard work of Fred and Jeanne Foster, and other Pennsylvania PKU families, the Insurance Committee of the PA House of Representatives recently approved proposed amend-ments to Act 191, which mandates insurance prescription plans to cover the cost of formula. On Monday, May 10, 1999 the committee voted 15-6 in favor of the proposed amendment, House Bill 854, which would require health insurance plans to also cover the cost of low protein foods. The proposed bill included a cap of \$2,500 per year per person, with no age limit. The requirement that a prescription be obtained in order to be reimbursed was removed. This Bill would not apply to persons employed outside Pennsylvania or whose health insurance is self-funded by their employer and therefore subject to ERISA rather than state insurance laws. The Bill has now been scheduled for a vote before the full House on June 8th or 9th. It will then go to the Appropriations Committee, to the Senate, and on to the Governor. It is important to contact your Representatives and Senators to seek

National Coalition of PKU and Allied Disorders

On March 19, 1999, a meeting was held in Massachusetts to form the National Coalition for PKU and Allied Disorders (NCPAD.) Representatives from a number of regional support groups (including MACPAD), food and formula companies, and newborn screening companies were present. All agreed that a national organization should be formed. The purpose of the national coalition is primarily to deal with national issues such as research, education, information, newborn screening, federal insurance issues and treatment standards. NCPAD is intended to supplement, not supplant, the existing regional organizations. NCPAD will be incorporated and operating within the next several months.

One of the first orders of business for NCPAD is newborn screening. A number

of problems with current newborn screening were discussed at the meeting, including a discussion of cases where existing screening systems failed and that failure resulted in failure to identify babies with metabolic disorders until they were injured or had died. Many of these problems seemed to result from the lack of understanding on the part of the medical profession of the importance of testing. Thus, an initial project discussed was outreach to obstetricians and pediatricians to inform them of the importance of newborn screening.

MACPAD'S ANNUAL MEMBERSHIP MEETING

MACPAD'S 2nd Annual Membership Meeting will be held on Saturday, August 7, 1999 from 10:00 am to noon. Board elections will be held. All members are encouraged to attend. If you are not yet a member, but would like to join, please come to the meeting. It will be held just prior to the picnic, at a convenient location. Details will follow in the mail, or contact MACPAD at (610) 380-8281 or by email at Info@pkumac.org.

NEW LAB AWARDED PA CONTRACT FOR NEWBORN SCREENING AND BLOOD TESTS

Pennsylvania residents should now send their blood samples to :
**NEO GEN SCREENING INC
110 ROESSLER RD STE 200D
PITTSBURGH PA 15220-9749**

In addition to more accurate phenylalanine levels, the new lab also tests and reports tyrosine levels. For more information, contact your clinic.

*Always remember to include the date and patient's name on your filter paper specimens!

CREATIVE FAMILY COOKING - Recipes and Menu Planning for PKU is ready to go to press!

After many months of work, MACPAD's first fundraiser is about to be unveiled. Over 125 exciting recipes, which include fruit pizza; roasted red pepper and asparagus pasta sauce; broccoli cheese pancakes; lemon meringue pie; and beetroot burgers are all ready for the chef. Over 150 pages of quick meal ideas, recipes, menu planning suggestions, tips to enhance the PKU diet, personal menu planning charts and information on low protein food suppliers. We've even included phe calculations!

Recipes have been collected from contributors in 20 states, Iceland and Canada and are divided into Soups

and Salads, Pasta, Rice and Potato Dishes, Vegetables, Sandwiches and Spreads, Sweet Treats and Potpourri. Included at the end of each section are blank pages for you to use to add your own favorite recipes to make this a book you will use and reuse!

All this for \$14.00 per copy!

The projected distribution date is June 1, 1999. Because this is our initial endeavor and the book is being professionally printed, the number of books available will be limited. So, order yours now!

To order your copy of **Creative Family Cooking - Recipes and Menu Planning for PKU** complete

this order form and mail with your check, made payable to MACPAD.

Name _____

Address _____

Phone _____

Email _____

Number of books @ \$14per
copy _____

PA residents add 6% sales tax _____

Amount of check enclosed _____

Mail to: MACPAD Cookbook
PO Box 6086
Lancaster, PA 17607

If you have any questions, call us at 610-380-8281, or email at Info@pkumac.org.

NAME THE NEWSLETTER CONTEST!

We are still accepting submissions for the Name the Newsletter Contest. The winner will receive a basket of low protein goodies!

To submit your ideas for the **Name the Newsletter Contest**, please complete this entry form and mail to: MACPAD, PO Box 6086, Lancaster, PA 17607

Name _____

Address _____

Phone _____

E-mail _____

My suggestion for the name of the newsletter are:

- 1.
- 2.
- 3.

Pilot Program for PKU Formula Distribution in PA

Karen Blackbird, R.D., M.P.A., PKU Nutritionist, The Milton S. Hershey Medical Center, Hershey, PA

Since October of 1998, the M.S. Hershey Medical Center's PKU Treatment Center has been involved in a pilot program for revised formula distribution in the state of PA. This article attempts to summarize the rationale for looking at a new means of formula distribution, as well as explain how the pilot procedure is set up.

How the current system works: Formula for PKU is ordered by the Division of Maternal and Child Health (MCH) and stocked in a central warehouse in Harrisburg. The formulas that are stocked are agreed upon by the three treatment centers in PA and MCH and then put "out for bid" by MCH to get the best price (they are required to do this even though only one company makes each of the formulas!). State health centers then order the formula from MCH for their specific patients and distribute it accordingly. The Division of MCH block grant pays for all formulas for children up to the age of 21 and women planning a pregnancy or currently pregnant.

How things work in the pilot program: My understanding is that the pilot program was designed largely to recoup reimbursement from insurance companies which cannot be done in the current system (since a family never receives a bill for formula, there is nothing to submit to the insurance company). In addition, under the current system, there is no provision for children with MSUD to receive any MCH assistance for formula.

The proposed system which is being

piloted is as follows: The family completes a packet of information, which includes income verification (copy of last year's tax statement), proof of residence and citizenship, insurance info, etc. The family is also asked to select (rank) 3 pharmacies that are convenient to them, through which their formula will be ordered.

The paperwork is sent to the Division of Children for Special Health Care Needs, where they evaluate income eligibility for funds from their division. The paperwork is then forwarded to First Health, which processes the insurance info and is supposed to contact one of the pharmacies to verify their ability to obtain the formula. After this, the patient info is sent to the Division of Maternal and Child Health, which sends a card to the family identifying that they are enrolled in the program. The family will take this card and a prescription for the formula (provided by the treatment center) to the identified pharmacy, which will then order the formula for the patient. It may take 1-2 weeks for the formula to arrive in the pharmacy, or longer for the first order, as some pharmacies are having trouble finding the appropriate distributor for the formula(s). (This is the stage where I am seeing the most difficulty).

The family then picks up the formula at their pharmacy (usually a one-month supply). The pharmacy bills the insurance company and whatever the insurance does not pay is billed to the Division of MCH, which pays the balance back to the pharmacy (out of the funds currently used to stock and distribute formula

centrally). During the pilot program, no co-pay is being collected from families. The Division of MCH does, however, eventually desire to establish a co-pay determined by income.

Well, having read all this, you are probably wondering when, and if, this will all take effect statewide. Although that has not been finally determined, July of 1999 is the targeted date to broaden this statewide. If you are involved in the pilot program and have pertinent feedback, PLEASE call Jack Means (717-863-8143) or Dan Brandt (717-783-7440). They need to hear from you if there are concerns about continuing this means of formula distribution.

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

Greg Reynolds 1/27
Daniel Gilbert 2/28
Amanda Bracero 3/5
Donnita Fox 4/14
Taylor Rodgers 4/19
Deborah Connelly 4/29
Jessica Smith 5/28
Rebecca Shulze 6/3
Zachary Allwein 7/7
Melinda Fouse 7/15
Jacob Smith 7/16
Charley Griffith 7/20
Todd Atkinson 7/22
Ken Barton, Jr. 7/23
Kim McDowell 7/27

Newborn Screening

Dean Jerrehian

There is a lot happening on the newborn screening front. First, on April 13, Representative Dennis O'Brien, Chairman of the Health and Human Services Committee of the Pennsylvania House of Representatives circulated a memorandum to Members of the Pennsylvania House of Representatives announcing proposed legislation (House Bill No. 1421) that would require screening for 21 additional disorders (only four are currently required to be tested for in Pennsylvania.) In that memorandum, Representative O'Brien also asks his fellow house members if they would like to co-sponsor the bill. As the more co-sponsors there are, the more likely it is that the bill will get passed, it is important to have as many co-sponsors as possible. Thus, all Pennsylvania residents should contact their representatives **now**

and ask them to co-sponsor this legislation.

Second, a number of other states have begun the process of expanding newborn screening. For example, thanks to the efforts of parents in Maryland, the Maryland Newborn Screening Advisory Council discussed expanding newborn screening at length in a recent meeting. The Council seemed generally in favor of expanding screening but believed legislation was necessary to make it a reality.

Third, on May 10 and 11, a conference sponsored by the American Academy of Pediatrics and the U.S. Health Resources Services Administration, was held in Washington, D.C. to "develop multidisciplinary recommendations to advance state newborn screening systems." The conference included a "Newborn Screening Task Force" comprised of physicians, parents, ethicists,

and public health officials. The task force presented five work group reports and heard public comment on those reports. The subject of the reports were as follows: (1) medical home and systems of care; (2) newborn screening and its role in public health, (3) economics of screening, (4) ethical, legal and social issues, and (5) implementation and assessment issues. Public comments will be incorporated into the conference proceedings and final recommendations of the task force. The most significant aspect of the conference is that it is occurring; the debate over newborn screening is taking a national stage.

If anyone has any questions or would like to get involved with any of these issues, please contact Dean Jerrehian at (215) 242-0810.

IMPORTANT! UNLESS YOU ARE A MEMBER OF MACPAD, YOU WILL NO LONGER RECEIVE THIS NEWSLETTER. To continue to receive the newsletter and other benefits of membership, become a member of the **Mid-Atlantic Connection for PKU and Allied Disorders, Inc.** Complete this form and mail with your check to the address below. Thank you for your support!

Name _____
 Address _____
 Telephone _____ Fax _____ E-mail _____
 Name of Person with PKU or Allied Disorder _____
 Birthdate _____ Metabolic Disorder _____
 Relationship of this person to you _____
 Clinic Affiliation _____

Please circle one of the following:

Individual Membership - \$15 per person Family Membership - \$30 per family
 Business Membership - \$50 (includes 20% discount on advertising in newsletter)

I am interested in :

Volunteering on one of the following committees: Activities Information Fundraising
 Serving as a contact for parents of children newly diagnosed with a metabolic disorder

For more information, please call the Mid-Atlantic Connection for PKU and Allied Disorders at (610) 380-8281 or E-mail at Info@pkumac.org

Return form to: MACPAD, PO Box 6086, Lancaster, PA 17607

**MACPAD HAS NEW
ADDRESS AND
PHONE NUMBER**

Address: PO Box 6086
Lancaster, PA
17607
Phone: 610-380-8281
Email: Info@pkumac.org
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!

**MID-ATLANTIC CONNECTION FOR PKU AND  
ALLIED DISORDERS, INC**

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