



Laura Johnstone turns over the Presidents' gavel to Judy Griffith

A Message From the New MACPAD President

It is easy to take for granted what we are involved with and do every day. Most of us have become accustomed to dealing with the PKU diet and lifestyle changes required to accommodate the diet. We have learned to weigh food, to decide what can and cannot be eaten at any given moment, and to deal with social eating issues such as parties, lunches and restaurants. We have adjusted our food purchasing habits, our eating out habits and our daily cooking habits. We have done all this and have gotten so good at it that sometimes we even forget that we are dealing with PKU.

And then one day something happens that disrupts our comfort with PKU. A child cries because he cannot eat what his friends are eating. An uncomfortable luncheon where nothing is served that we can eat. A battle over drinking the daily formula or a dinner rut that we just can't seem to get out of. On these occasions, I hope (cont. Page 5, col.1)

MACPAD Is Beneficiary of Memorial Donations

Long time MACPAD members and supporters, Michael and Kathleen Gorman and daughter Victoria were saddened by a recent loss. Late last year, Kathleen's father, Harry E. Bowers Jr. passed away. It was one of his fondest wishes to see a "treatment" or a cure for PKU. At the time of his death, family members requested that in lieu of flowers, donations be made to MACPAD. As the donations arrived, we noted that most individuals included a note about Mr. Bowers' love of his granddaughter Victoria and his hope that someday she would not be restricted to a low protein diet.

In his honor, MACPAD has developed a research fund with all monies collected going to PKU research. The Gormans' attended **CONFERENCE 2000**, the MACPAD conference held last August and heard Dr. Holmes Morton outline his view of current and future methods of dealing with metabolic disorders. It is with this in mind that the Board of Directors has decided to add to the memorial donations and make the contribution to his clinic.

Clinic For Special Children to Benefit from Research Fund

For 12 years, a small, but world renowned, clinic in Strasburg, PA has been serving children with metabolic disorders. Dr. Holmes Morton, the founder, has been presented with medical problems due to over 70 different genetic

disorders or syndromes. The Clinics mission also seeks to advance methods of newborn screening and follow-up services and to further clinical research.

The expansion of the clinic building in December 2000 accommodates the need for the growth in staff and maps progress toward achieving full potential as a center for diagnosis, treatment and research of rare genetic disorders. The clinic proposes to investigate the relationship between clinical variants of PKU and MSUD and the underlying gene mutation. This study will increase our understanding of why some individuals with PKU or MSUD have milder neurological symptoms than others.

Dr Erik Puffenberger has found that two different mutations cause the Amish variants in PKU. Within the Amish population, even within some Amish families, the clinical phenotype varies from mild hyperphe to the severe classical phenotype. He suspects the mutations that cause the Amish variant of PKU both interfere with the binding of biopterin to the phenylalanine hydroxylase enzyme. PKU may be more or less severe based on the availability of biopterin in the diet. Therapeutic trials using biopterin as a cofactor may provide an alternative therapy for individuals with these particular mutations. MACPAD has donated monies for the purchase of materials used in the process of gene analysis using an ABI Prism 310 genetic analyzer as well as biopterin cofactor for clinical trials.

**Happy Birthday
To Our MACPAD
Members!!**



Heather Matthews- January 16
Stephen Schulze- January 17
Greg Reynolds- January 27
Daniel Gilbert- February 28
Donnita Fox- April 14
Deborah Connelly- April 29

Children Are Like Kites

You spend a lifetime trying to get them off the ground. You run with them until you're both breathless- they crash- you add a longer tail- they hit the rooftop, you pluck them out of the spout- you patch and comfort, adjust and teach. You watch them lifted by the wind and assure them that someday they will fly! Finally they are airborne, but they need more string and you keep letting it out and with each twist of the ball of twine there is a sadness that goes with the joy, because the kite becomes more distant and somehow you know that before long that beautiful creature will snap the lifeline that bound you together and soar as it was meant to soar, free and alone. In its place will come friendship that will have its own rewards.

...Author unknown



Grandma's Corner

Are you a grandmother of a child with a metabolic disorder? Ever have a question and you just can't decide on the answer? Wish you could talk to your Grandma?

This column will feature questions that our readers send in. The questions will be given to a panel of grandmothers and the answers will appear in the next issue. So send your questions to MACPAD, Attn: Grandmother!

What kind of snacks could a grandmother keep in the house for when the grandchildren with PKU visit?

The type of snacks will depend on the type of PKU and the daily phe allowance. Some children can have things that others may not. Mostly, keep low phe items for snacks. My grandchildren love cotton candy and it is a free food! I bought a Salton Cotton Candy maker and it makes great cotton candy. Kool Aid Kool Pops, in all flavors are also free and a good snack.

How do you handle taking the children on trips? What foods do you take and how do you keep things cold?

For traveling in the car, any of the candies or cereals that they normally have at home are

wonderful. Also, fresh fruit is a great traveler and not a problem to carry. My daughter recently took her two children with PKU (ages 3 ½ and 8 months) to Germany. She was quite concerned about their foods but her fears proved groundless. For traveling overseas, she was told not to put the powdered formula in premeasured bags as it might present a problem at customs. Instead she just packed a suitcase full of formula and kept a couple in her carry on luggage. She also took cereals and cookie type snacks in baggies in a small cooler, which was kept on the plane with her.

Uncle Henry's Pretzels

Special Sale: an 8 oz case of Low Protein Pretzels for \$19.50!

Regularly priced at \$20.25. Please be advised, due to rising costs there will be a price increase in the next few months. Also be aware that UPS has raised their base price, plus they also now charge a fuel surcharge. But for this sale all shipping prices remain the same. Please call 717-445-4690 to place your order. You can also order at www.unclehenry.com.

Ener-G Foods

Since 1962 Ener-G Foods Inc. has been supplying wholesome and good tasting foods and mixes for diet-restricted individuals. We now offer 45 different low protein items. And soon we will have 4 new low protein pastas. For more information, please check us out on line at www.ener-g.com or give us a call at 800-331-5222

In the Words of Children...



By Victoria "Tori" Gorman

Hello, my name is Tori Gorman. I am seven years old and in the first grade. I have PKU. PKU means that I can't have a lot of foods that other kids have. My diet keeps me healthy. I drink my milk every day. I love my milk. My favorite foods are rice-a-roni, French fries, spaghetti and noodle soup. I had a pizza party at school yesterday. My mom sent in my pizza. I like my pizza, too. I have chocolate sorbet, fruit snacks and cookies for treats. I play soccer and softball. I take tap, jazz and ballet lessons. My favorite subjects in school are math and gym.

This is the Third 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 along with a photo. or email Info@pkumac.org.

Random Reflections

It is with great hope and prayer that I begin writing a column for the MACPAD newsletter. I chose Random Reflections as the name of my column hoping that some of our family's learning experiences can be shared. Hopefully, I will be able to share some helpful information that our family found useful through the years on the sometimes "bumpy road" of raising a PKU child. So much has happened in the past 20 years to make the information and understanding of PKU so much more readily available to "new members of the PKU family". We were not as fortunate to have all of the latest information available to us or a support system to direct our steps. Each column will try to give a helpful reference source or publication, a "food thought" or a recipe or just "random" thoughts that worked for our family.

Joe is 20 years old and a sophomore at Furman University in Greenville, South Carolina. His brother Dan is 24 and does not have PKU. Dan married in June of 1999, and so my husband and I now have a "daughter" and Joe has a "sister" named Mary. Dan and Mary live also in Greenville...a long 600 miles from Roaring Spring, Pennsylvania. We rejoice that the three of them, as they each start new phases of life, can have each other as a support system.

A booklet given to our family on the day of the official diagnosis of Joe's being a PKU baby was a booklet entitled "Living with PKU" published by the Inherited Metabolic Disease Clinic of the University of Colorado Health Science Center in Denver Colorado. It was updated in 1990. Written by parents of children with PKU, I would recommend it to all parents. It is available through

the pkunews.org website. Your clinic may also be able to assist you in getting a copy from the Mead Johnson Company who provided the financial support for its publication. There are many helpful hints in it and I will be sharing many of those with you at various times in this column. A lot of the hints were helpful to our whole family.

Our older son at the age of 3 ½ "pretended" to read this book because he knew that we referred to it for encouragement often. One of my fondest memories of Joe's early weeks in our home was when I would be feeding Joe and his brother would come along side me with the Living with PKU booklet and "read" to me. "This book says that if we do what it says in here my brother Joe is going to be O.K.". It was the start for me of watching our family begin a support system for each other as we made the many adjustments that would become second nature to all of us.

A little nugget of wisdom...any siblings of the newly arrived PKU child need a "simple" explanation of the diagnosis. They are watching and hearing the "extra" attention being given to this new arrival in the family. It is important that they too develop a level of concern and interest in their PKU sibling's welfare.

Food Thought

One of the ways to control the "need to feed" in a low protein diet is to offer foods with a high degree of satiety or feeling of fullness. One FRUIT that our family depended on were APPLES- SLICED OR SAUCED! To add to the pleasure we would sprinkle cinnamon and brown sugar...both phe free foods. Domino sugar sells dispensers that are the perfect size for the toddler to enjoy sharing in the preparation of their "treat"...our dispenser is a "baseball catcher". When our family is looking for the ready mixed sugar/cinnamon dispenser

the phrase “where is the Catcher?” is understood. Joe enjoyed preparing this snack and it became a healthy alternative to “junk food”.

Discipline is to teach- Discipline is important to be taught to all children. Children born with PKU require a special discipline as it relates to their in-take of protein foods on a daily basis. They must from the beginning, understand that these low protein food choices are NOT negotiable. As children mature, this discipline enables them to exhibit self-control and adherence to necessary diet guidelines. This develops within them traits of self-esteem and confidence on their journey in life.
Cindy Hoover

Applied Nutrition

Maureen Finkel has notified us that their website has been updated and they are requesting everyone visit the site. The new look at <http://www.MedicalFood.com> includes the Amino Acid Blend for PKU and the line of Complex MSUD products.

T-Shirts

MACPAD T-shirts are still available. We have, in stock, adult sizes x-large, large, medium and small. In children's sizes, 6-8 and 10-12 are available. All are 100% cotton, gray shirts with the burgundy and blue MACPAD logo. If you would like to order one, please use the form attached to this newsletter.



Activities to share with 2-3 year olds.

Animal sounds: Take turns guessing which animal you or your child is imitating. But, don't guess immediately! Your child says, “meow”. “That can't be a dog, you reply, and it isn't a fish”. After a couple guesses, choose the cat!

Categories: Take turns listing animals, fruits, things we wear or other familiar items. List them on paper then count them.

Grow an indoor lawn: Put a sponge in a dish half-filled with water. Sprinkle with seed, and then push the seeds into the sponge with a fork until seeds are wet but not underwater. Water the bottom of the sponge as needed. In a few weeks, you can mow your “lawn: with scissors.

Paint blobs: Fold construction paper in half, drop tempera paint into the fold, and then let your child press on the outside. Some may want to finish the picture with crayons.

Another cooking demonstration is being planned, this time in the Philadelphia area. Watch your mail or check with your clinic for details.

PKU Life

New computer program offers 60-day money back guarantee.

PKULife was developed using specifications from people who actually manage the PKU diet. Before it was released, PKULife 1.0 was beta tested for over 4 months, resulting in great excitement from our beta testers. Since PKULife was released, we have received great responses from people who are actually using PKULife on a daily basis. For these reasons we are very confident that PKULife can help you too! Therefore, we guarantee we will give you a refund for the full price of PKULife 1.0, if during the 60 day trial period, you do not see a positive change in your PKU diet management! For promotional details go to www.pkulife.com/promotionrules/html.



MACPAD has sold 645 “Creative Family Cooking” cookbooks!

As we enter the next printing, there will be a price increase to \$16.00. There are two reasons for this change- an increase in postal rates and our desire to donate \$2.00 from each cookbook sold to the **MACPAD Research Fund**. You may order a cookbook by using the form enclosed with this newsletter.

(Cont. from page 1)

that you will remember that MACPAD was formed to provide you with that support. There are

many people in our area that are dealing with these same issues and who can help you get through these difficult moments. What is most important is for you and your children who have PKU to feel that you are not alone.

As the new President of MACPAD, I would like to reinforce MACPAD's mission of offering support and creating a connection among PKU families. We have enclosed a questionnaire that will give you the opportunity to tell us what MACPAD can do to make dealing with PKU a smoother road. We also need you! For example those of you who have been living with PKU can provide immeasurable support to those who are still struggling with understanding and learning about what it means to have a child with PKU. Everyone has something to offer in support of others- and in the process I hope we can all become a closer and stronger community.

I look forward to serving as the President of MACPAD and with all of us working together; I know the organization will become an integral part of our lives.

Judy Griffith
Mother of 3 boys, 2 with PKU

Pennsylvania- Newborn Screening

Representative Bell introduced a new bill expanding newborn screening in Pa. in the Pennsylvania Senate on January 30, 2001. Look for more information about Senate Bill 166 in the next issue of Connections.

New Jersey- Newborn Screening

Assembly Bill No. 3156 was introduced in the New Jersey Legislature on January 23, 2001. The bill, sponsored by Assemblymen Doria and Felice, expands the number of disorders included in the newborn screening

program. Currently, the state tests only for hypothyroidism, galactosemia and PKU. The new law will require screening for a number of other disorders including MSUD and homocystinuria.

Legislative Update

Pennsylvania-Low Protein Modified Foods

Pa House Bill 854, sponsored by Representative Nicholas Micozzie and introduced in the 1999 legislative session, will amend the medical Foods Insurance Coverage Act of 1996 to require all individual and group health insurance policies to provide insurance coverage for both the formulas and low protein modified food products. The Act includes coverage for individuals with PKU, MSUD, galactosemia and homocystinuria.

The legislation places a \$2,500 annual cap on insurance coverage for low protein modified foods for insured individuals. House bill 854 was sent to the House Insurance Committee on May 10, 1999 and passed by the House on October 18, 1999. In 2000, the bill was under review by the Senate Banking and Insurance Committee. The Pennsylvania Health Care Cost Commission reviewed the bill and issued a report in May 2000. The report reviewed arguments in favor of and against the mandated benefit without drawing any conclusions.

The 2000 legislative session ended on November 30, 2000 before HB854 was brought before the State Senate for a vote. At the time of this writing, we are waiting for the bill to be reintroduced by Representative Micozzie. Anyone who lives in Pennsylvania may want to contact Representative

Micozzie, along with your own representative, to urge re-introduction of this bill.

Activities to share with 4-6 year olds.



Animal lotto: Cut pictures from magazines or draw pictures of animals. Try to get two of each kind. Try also to get adults and babies. Include birds, reptiles and fish. Then play matching games. Match the same kinds of animals or match all the babies.

Homemade puzzles: Paste a picture on a piece of cardboard, and then cut it into several pieces. You can even use duplicate photos from recent snapshots.



New President Judy Griffith discusses plans for August 4, 2001 picnic with new Board members Lynn Trump and Carol Barton.

Mark your calendars the annual picnic is scheduled for Saturday, August 4 at the Weavers Farm in Denver, PA. Over 200 people enjoyed the fun and food at last years' picnic; so make sure to circle the date! New Board members Lynn Trump and Carol Barton, co-chairs of the event, are planning an exciting day!

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

Name _____
Address _____
Telephone _____
Email _____
Name of Person with Metabolic Disorder: _____
Date of birth _____
Metabolic Disorder: _____
Metabolic Clinic Affiliation: _____

I would like to:

- Become a member of MACPAD (first time member fee: \$30 per family/\$50 per business)
- Renew membership (\$10 annual family renewal, \$50 per business)
- Purchase a cookbook (\$16.00; PA residents add \$.96 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.
- Donate monies to the MACPAD Research Fund.
- Submit a question to "Grandmas Corner"
- 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.

MACPAD is eligible to receive contributions through the United Way agencies of Southeastern Pennsylvania (Specific Care code number 12456) and Lancaster County and Blair County, Pennsylvania.



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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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