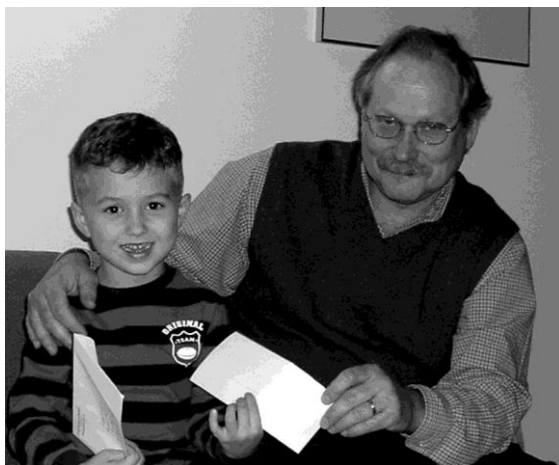


“PKU WALK” FUNDS WILL BENEFIT PKU RESEARCH



Charley Griffith presenting the check to Dr. Holmes Morton

The Board of Directors of MACPAD met on October 12, 2002. Each member had reviewed a copy of two proposals that were submitted to request funding. The decision was made to divide the funds and present \$24,200. to Dr, Holmes Morton at The Clinic For Special Children and \$2500. to Dr. Barbara Burton at Children’s Memorial Hospital in Chicago. Following is a brief description of both projects.

The Clinic For Special Children in Strasburg, PA has operated for 12 years as a specialized pediatric non-profit clinic to diagnose, treat and research metabolic and other genetic disorders. The research has focused on maple syrup urine disease, gluteric aciduria, crigler-najar syndrome and other genetic disorders. Dr. Erik Puffenberger, a molecular biologist, who is director of the Clinic’s laboratory, has sequenced the PAH gene in several Amish and Mennonite patients and has found three different mutations in the gene. All three mutations are found in European populations and have been reported to be associated with relatively mild variants of PKU. One mutation that is found in both Amish and Mennonite population’s results in an amino acid substitution near the biopterin binding region of the enzyme and has recently been reported to be responsive to biopterin.

Under the direction of Dr. Holmes Morton they plan to study gene mutations of the phenylalanine hydroxylase gene that are biopterin responsive. Specific mutations of the gene produce an enzyme that can be activated by pharmacological doses of the cofactor biopterin. PKU patients with such mutations may have tolerances for dietary phenylalanine that vary widely. Dr. Morton proposes to do mutation analysis on his Amish and Mennonite families with PKU to determine the distribution and total number of mutations within these populations. He will also be conducting biopterin loading studies and 12-month treatment trials to determine the effect of tetrahydrobiopterin upon amino acid tolerance and neurological signs. He hopes to develop guidelines for the evaluation of mutations for biopterin sensitivity that can be applied to other populations.

The PKU Clinic at Children’s Memorial Hospital in Chicago, under the direction of Dr. Barbara Burton, is conducting a research project designed to determine what fraction of patients with PKU respond to treatment with the drug tetrahydrobiopterin, also referred to as BH4. Some start-up funds for this project have been provided by the Mid-Atlantic Connection for PKU and Allied Disorders, Inc. The PKU Organization of Illinois provided most of the funding. Early research in other countries has indicated that the blood phenylalanine level in some patients with PKU can be

lowered by using BH4, a vitamin-like substance. In patients who respond to the medication, it may be possible to increase the amount of phenylalanine in the diet or conceivably to even eliminate dietary restrictions. Research thus far suggests that patients with mild PKU are most likely to benefit from the medication but too few patients with classical PKU have been tested to draw any firm conclusions. The study at Children's Memorial will include children and adults 3 years of age or older with either mild or classical PKU. It will involve allowing the blood phenylalanine level to rise for several days then giving a single dose of the medication and subsequently doing serial phenylalanine levels over 24 hours to determine whether or not a decline is observed. If some patients are found to respond to the medication, the plan will then be to continue treatment while testing to see how much relaxation of the diet is possible. DNA analysis of the phenylalanine hydroxylase gene is being performed on study subjects to determine if patients with certain changes (mutations) in the PKU gene are more likely to respond to the medication than patients with other mutations.

BH4 is classified as an investigational new drug in the United States and can only be prescribed in the context of a research project with Institutional Review Board approval. Questions regarding the study can be addressed to Dr. Burton at 773-880-4462 or bburton@childrensmemorial.org.

Mark your calendars! Important dates to remember!



Saturday, March 29, 2003

Coming this spring- a low protein bread and pizza-baking demonstration! Hershey Medical Centers' dietitian, Karen Blackbird, is planning an exciting day in Lancaster County, PA (location to be announced). Complete and detailed information will be available in the next edition of "Connections"



Saturday, May 3, 2003

Our second annual PKU Walk-A-Thon is scheduled for Saturday, May 3rd at Washington Lake Park in Washington Township, NJ! Please join us for a day that is guaranteed to be educational, fun and inspiring. PKU vendors will join us along with speakers, food, craft tables, raffles, balloon art, face painting, a magic show, games and much, much more! Remember that **100% of all money raised goes directly towards PKU research** such as the projects we were able to support this year. Stay tuned for more information in upcoming MACPAD newsletters or call Janice @ 856-478-0577 or Deb @ 856-223-0301. You can support the walk even if you are unable to attend.

Saturday, August 2, 2003

The annual MACPAD PKU picnic!

Meet The MACPAD Vice-President



My name is Ken Barton Sr. I have been a member of MACPAD since the inception of the organization. I was elected to the Board of Directors and then to the office of Vice-President, the office I currently hold.

I am the father of two very wonderful children, Ken Jr. 11years old and Kara who is 8. Ken Jr. has PKU. After Ken Jr. was born, I learned a lot about PKU. Ken Jr. was born on July 23, 1991. After the pku diagnosis, and telling two new parents that their son has pku (which was not handled very well by the nurse at the hospital), we had to go to Hershey Medical Center, where we met Dr. Cheston Berlin and Karen Blackbird. Both were very nice and reassuring that this would be okay. A few weeks later there was a PKU picnic scheduled and we were invited. We found out how good Dr. Berlin really is. He came up to us at the picnic and took our three-week old son right from my arms, as we stepped out of the car and he walked away!!! He wanted to introduce "his" newest PKU child! The staff at the State Health Center in Lancaster and the HMC staff were definitely guiding lights at that time. I had never heard of PKU before Ken Jr. was born and now I was learning all there was to learn. We were not concerned about the second child having PKU. After all, if you have to learn the special diet and adjustments necessary for one child, what would be the big deal if another had PKU??!! In 1991, it was very difficult to imagine that life would be okay for Ken Jr. or his parents. Now, we know we can live with it and be thankful for his otherwise good health. And having an organization like MACPAD, you know if you have any questions, friends are just a phone call or a mouse click away.

I have been a lifetime resident of Lancaster County and I currently reside in West Lampeter Township. I have been employed by the City of Lancaster as a firefighter for 18 years. I am currently a lieutenant on a ladder truck. I have attended Millersville University and Harrisburg Area Community College. I am working towards my Associates Degree in Fire Sciences. In my spare time, I enjoy my children, my family, spending time with the special woman in my life, travel, hunting, fishing, the mountains and most out door sports. Autumn is one of my favorite seasons followed right behind by winter. And of course, as all homeowners know, the ever present need to "fix" something in the house takes time from every week. I am a vice-president in the city firefighters union, Local 319,IAFF, and president of the Lancaster City Firemen's Relief Association. I am also the treasurer of Buck Hollow Recreation Association, which is a firefighters social farm. I am on the steering committee of the Lampeter-Strasburg Recreation Commission, currently planning a new rec center for this area.

I find the hardest part for me as a parent is trying to find, and keep the variety in Ken Jr.s' diet. Some days it is difficult to make meals that are nutritious, low-protein and not repetitive. But, he is a trooper and helps me!

I would like to thank everyone that has been instrumental in making MACPAD what it is today and continue to keep it running. Their dedication has helped push MACPAD to the top. And thanks to all who have a part in the annual picnic.

I was not ready to have a "problem" with a son who I long awaited to carry on my family name. However, now I know it is not a problem. PKU has been a challenge and I'm sure there will be more. But with the help of family and friends, it will be just a small bump in the road.

Dear Jennifer...

The latest feature of the MACPAD newsletter! **A "Dear Abby" column just for teens and young adults with PKU.** Do you have a question that can only be answered by someone who truly understands what it means to have PKU? Read Jennifer's' story on page 6 & 7 of this newsletter. Then, if you have a question for her, you can email Info@pkumac.org, Attn: Jennifer or send your question to MACPAD, Attn: Jennifer, P.O. Box 6086,Lancaster, PA 17607. Names will not be used, if requested.

MEET A MACPAD BOARD MEMBER



Grandmas' Corner

Dear Grandma, Do you have any special holiday traditions that you have adapted for the PKU diet?

My husband Dennis and I have lived in Myerstown for 32 of our 34 married years. We raised sheep for 25 years, had a large garden, made candles and have dabbled in various and assorted crafts. I became a quilter about 25 years ago and have taught quilting at the local Vo-tech and high school.

We have 3 children. Andrea is an Organizational Development Specialist for Air Products Inc. Allison is an x-ray tech at Lebanon Orthopedics and the mother of Logan, 3 years old, and Alyx Katrina, 7 months old. Peter is a junior at Bloomsburg University majoring in Business Administration.

In 1980, I started a candy making business in our kitchen and it grew to be quite an operation consuming far more time than I could manage so I sold the company in 1990 and it is still in operation.

I then became a seasonal worker in the garden and floral industry, until I was needed to care for Logan, who has PKU. We found his diet to be quite challenging. We have learned so much and are thankful to the MACPAD network for all the support and information they provide.

This summer, Dennis and I moved to our retirement home and are striving to simplify our lives and have more free time with our children and grandchildren.

Remember when you move to change your address with MACPAD. We want to be sure you continue to receive our newsletter.

Well, it is time for the holidays and time to make something special for our children. In our family Advent Calendars are a tradition. Advent calendars count down the days until Christmas, each day you open a door and the last door tells you it is time for Santa to come. In our family, we like the calendars that have a piece of chocolate behind each door. We have 5 grandchildren, 3 do not have PKU and 2 do. We buy 5 calendars but, for two of them, we open them, take out the plastic inside that houses the candy and make our own with the mold of each piece. When the candy is taken out of the plastic insert, 24 little molds are inside. We just melt chocolate almond bark and refill each mold. After the candy hardens we put it back inside the calendar and reseal it. The children are aware that they have their special chocolate inside, but they love the thrill of opening each door to await Christmas Eve.

Another tradition in our family is that I make each child a gingerbread house of their very own. For the three without PKU, I make a traditional gingerbread cookie recipe and roll it out and cut out the shapes we made to design a small house for our 2 with PKU, we either use Virginia Schuetts recipe for sugar cookies or her recipe for gingerbread. We usually design a front for the house, a side and a roof. You make two of each design. For the back of the house we do nothing, but for the front, which is the same as the back, we cut a front door and windows when the gingerbread is fresh out of the oven and still warm. After you cut the pieces, let it cool before removing from the cookie sheet otherwise it will break. What I have found is the easiest to do is to put the dough directly onto the cookie sheet then roll it out. I then lay my pattern on the dough and use a sharp knife or a pizza cutter to etch the design into the dough. After it is baked, the pattern is still on the dough and is easy to recut with a sharp knife. We use Royal Icing, which hardens quickly to seal the seams of the house and roof and to decorate with. (recipe follows article) We stick an assortment of candies onto the house with the icing for decoration. The houses turn out really cute and

everyone loves them.

Royal icing: 3 egg white at room temperature, 4 cups confectioners sugar, ¼ tsp cream of tartar. Beat all the ingredients at high speed for 7-10 minutes. It should be pretty stiff. Put it into a decorating cone and enjoy! Keep unused frosting in the refrigerator. Hope you all have a wonderful holiday season and "Happy Baking"

Grandma



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Our mission at Ener-G Foods as one of the country's foremost producers of foods for diet-restricted individuals is to provide a wide range of ready-made foods and mixes that are wholesome, nutritious, risk free and good tasting. We are constantly responding to the demand for special diets with research, innovative products, and convenience foods.

Since 1962, when we first created low protein products for renal pre-dialysis patients we have striven to meet the challenging requirements for diet restricted consumers. We not only offer wheat free, gluten free products, but also products for low protein diets, egg free, and dairy free products. Our bakery is dedicated to wheat free, gluten free baking, guaranteeing that contamination from gluten will not occur. Our innovative packaging gives our products a 1-year shelf life without the need for refrigeration. We bake our products as orders are received to insure that the freshest product is available.

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Phone: 206-767-6660 Toll Free 1-800-331-5222

Fax: 206-764-3398 or email WWW.Ener-G.com



New for January 2003 – A Frequent Buyers' Club designed to give rewards to regular customers! This program will give customers who order monthly, convenience benefits, as well as yearly savings. Please call Customer Service at option 2 using our toll free number for more information.

Good News for everyone who has been waiting for the new Cream Cheese products. Plain Cream Cheese, Herb and Garlic flavored Cream Cheese and Cheese Wizard – a Cheddar flavored cheese spread is now available. Try the Cheese Wizard with toasted Artisan Bread rounds. Everyone will love this **melted** on their favorite steamed vegetables! Porridge is also available to order. It can be used in the traditional way as a hot cereal or as an ingredient in baked goods. Try the "McNugget" recipe on our website to get your creativity charged.

Coming soon...Speed up your meal preparations with two new easy to prepare pasta and sauce combinations – Orzo Alfredo and Roasted Garlic and Broccoli Couscous.

Check out the Cambrooke Foods web site and see the range of new recipes available for using our delicious products to create more delicious foods for your family.

We are happy to announce our new Clinic Store Program, which has been initiated by two U.S. Metabolic clinics and one Canadian clinic. These clinics are maintaining a store of Cambrooke Foods' products to provide directly to their patients. The Clinic Store concept, which was piloted in the US by Emory University, has proven to be a much welcomed and successful program. Ask your clinic if they can provide this service to you.

Visit our website regularly for new products and join our mailing list (easily done by e-mailing us or calling us) so you will be advised of special offers. Returning to diet? Call us for suggestions to ease back into a "low pro life". We are always open to serve you. Call toll-free (866) 4 LOW PRO / (866) 456-9776 or over our website at www.cambrookefoods.com. If this is not convenient for you, you can mail or fax your orders to us.

Dear Jennifer...



“Life without Diet...Diet For Life

My name is Jennifer Burkel and I am a 30-year-old adult with PKU. The reason why I volunteered to write this article is because I know there are adults and teenagers out there who are struggling with the diet. Some of you are even contemplating discontinuation of the diet. Although I have no children of my own, I can imagine how difficult it must be for the parent of a young child to look at your child and wonder if he or she will be okay and live a normal life. Many adults have been off the diet for a very long time and have not yet gone back on. If I could get one adult back on diet, help one teenager continue, or give a parent hope that my goal will be accomplished.

I was on diet until I was 5 years old. The doctors did not know then what they know now about PKU. The belief was that your brain was fully developed by age 5 and that you were out of danger of high phe levels. The PKU diet was then discontinued. I was off the diet for 16 years. I started back on the diet 9 years ago after learning from another PKU parent that the belief is now “diet for life”.

Although I was an average student in school, it was a struggle. I had a very difficult time in math even with excessive tutoring. The harder math got, the more difficult it became for me to comprehend. I had a hard time learning new math skills because I could not concentrate or get clear pictures in my head.

I had very low self-esteem and was shy. I thought I was ugly. In high school, I would go to dances but never danced because I was afraid of what people might think of me. I was constantly very tired and depressed. I was very withdrawn and spent the majority of my time alone. My head always seemed kind of fuzzy and I could not get clear pictures in my head. I had mood swings that made me almost impossible to live with. At that point, I had no idea that these were all symptoms of high phe levels. At times I even denied that anything was wrong.

The older I got the worse my symptoms became. I had episodes of blacking out and nearly fainting. When I was 16 I had an episode where I was experiencing symptoms of a stroke. I had numbness in my arm and leg and my speech was slurred because my tongue was also numb. Although, I did not have an actual stroke, the results of the MRI showed white spaces in my brain, which I later learned in an issue of National PKU News was a symptom of high phe levels.

Once I found out that these were all symptoms typical of people with PKU who were off diet, I was anxious to go back on because I desperately wanted to feel better. It was the start of a new life for me. Returning to the diet was the best thing I ever did for myself. I have had many wonderful and positive things happen to me since going back on diet. I think that the most important thing that changed was that I got my self-confidence back. All these positive changes are a result of getting my self-esteem back, which would not have been possible if I had not returned to diet.

The first thing I did was get my driver's license and move out on my own. One thing I would never do before was dance; now you cannot get me off the dance floor without a surgeon! I am a much more pleasant person to be around and very sociable. The mood swings are gone. I actually have an imagination now because I can get clear pictures in my head. I recently took and passed a very difficult exam to become a licensed property and casualty insurance agent in Pennsylvania. Many people who do not even have PKU fail the first time! I am a part time student in pursuit of a degree in Business Administration. I actually got my first final grade of “A” in math, but my biggest accomplishment is that I am an honor role student with a GPA of 3.5!

My attitude is that there are worse things out there than PKU and are not treatable. We should all (parents, children and adults) consider ourselves very lucky compared to those who are less fortunate. There are some people out there with a terminal illness. PKU is treatable, but ONLY through diet. Another thing that motivates me is that I do not want to go back to feeling the way I was feeling. Sure, I have good days and bad days and yes, it is frustrating sometimes. Once in a while I give in to temptation. Don't we all have good days and bad days and frustrations in life...PKU or not? I take PKU one day at a time. That has helped me a great deal. It is important to realize that you are in control of PKU. Don't let PKU control you.

Another thing that I highly recommend is that parents, teenagers and adults get active with PKU. Go to the conferences, volunteer some time, go to the

camp and maternal PKU retreats. I found that the more I get involved with PKU the more successful I am on my diet. Put yourself in situations where you are around people who understand.

Parents, be patient with yourself and your children and have faith. I am not a parenting expert and am in no position to give you advice. What I recommend is that you read "The Child Who Never Grew" by Pearl Buck, the famous author. Pearl Buck had a daughter who had PKU and was left untreated. I think you will find the book very inspirational and I highly recommend it. I got my copy from Amazon.com.

Teenagers, PKU is all about you and your health. Do what is best for you and make the right choice. Be a leader, not a follower. Don't worry about what your friends will think of you. If they are truly your friends, they will accept who you are and that PKU is a part of you. Don't be afraid to explain PKU to them and answer questions. Questions don't hurt, ignorance does.

Remember to send your questions to "Dear Jennifer..." see page 3 for details. Your question and the answer will appear in the next edition of the MACPAD newsletter.

Random Reflections

A lasting legacy to love reading and learning is essential for our children in today's world!

I have been tutoring first and second graders in our elementary school for the past few years. It has been a real joy! Parents can make a huge difference by showing their child the fun and reward in reading. If you are interested in reading and learning, most likely when introduced to your child in the early years, they will be as well.

Reading can take us anywhere and expose us to who, what, and where of our world! So often television, computer and video games take the place of reading as entertainment for our children.

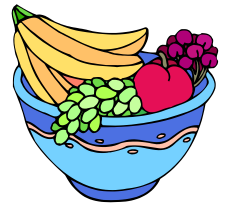
We need to motivate and encourage by finding books of interest to them and also to allow them to select books for themselves. Be a role model for your child by keeping reading material easily accessible, visit the local library, and area bookstores. Most local public libraries offer children's story hour, and reading incentive programs. If your child is in a pre-school program or day care program, inquire as to the reading introduction that

is being presented at their facilities. Children arriving in first grade need to understand their letters (and the correct direction they are written). Working with these letters in the early years is most helpful to the process of early childhood learning.

Set a family reading or some other organized learning activity time. Preparing foods and cooking is a helpful activity. I have included some suggested storybooks presented to me through the nutrition center at Penn State University. Learning is a skill and like other skills improves with practice!!

Give your child the practice and motivation that he or she needs to develop life-long learning skills.

Fruit Filled Storybooks...



Oliver's Fruit Salad by Vivian French (Orchard Books, 1998)

Oliver enjoys choosing real fruit in his grandfather's garden and at the supermarket with his mom, but he claims he doesn't like to eat fruit until he tries fruit salad.

Eating the Alphabet, Fruits and Vegetables from A to Z by Lois Ehlert (Harcourt Brace & Company, 1989)

This picture book encourages you to eat your way through the alphabet by introducing you to a variety of fruits and vegetables for each letter. Excellent descriptions of many fruits and vegetables are included in the back of the book.

Fruits, First Science Discovery Book by Gallimard Jeunesse and Pascale de Bourgoing (Scholastic by arrangement with Editions Gallimard, 1989)

This book contains plastic pages that allow the reader to look inside different kinds of fruits. Pictures of where the fruit grows are also included. Over twenty fruits are depicted in this book.

Editors note: This newsletter is meant to relay information about products and individual feelings. We do not attempt to replace advice from your physician or clinic on the treatment of metabolic disorders.



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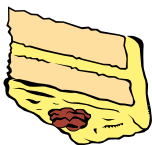
Contact us at 1-888-640-2800 or info@dietspec.com for he latest on our delicious frozen pizzas, breads and cheese as well as our kitchen staples: baking mixes, pasta, rice, sauce mixes and cookies!

New recipes available on our web site: www.dietspec.com

Want the latest information? Send a note to dietspec.com with your email address and you will be the first to know about the exciting new products planned for 2003!

We look forward to hearing from you!

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Basic Cake recipe

- 2 2/3 cups dp low protein baking mix
- 2/3-cup water
- 1 1/4 cups sugar
- 2 tsp. vanilla extract
- 2-1/2 tsp. low sodium baking powder
- 1 medium egg
- 1/4 cup shortening 1/4 cup + 2 Tablespoons water

Heat oven to 350 degrees. Grease 2 round layer pans 9x1 1/2" or 13x9x2". Dust pans with baking mix. Mix together dry ingredients. Add shortening, 2/3-cup water

and vanilla. Beat 2 minutes. Add egg and remaining water and beat 2 minutes longer. Spread batter in pans. Bake until wooden pick inserted in center of cake comes out clean, approx. 30 minutes.

18 servings Per serving: 155 calories, 0.33 gm protein, 28 gm carbohydrates, 12 mg sodium, 63 mg potassium, 18 mg phenylalanine



HAPPY BIRTHDAY TO OUR MACPAD FRIENDS!

Brittany Collins	November 24
Matthew Jerrehian	October 4
Brendan Dockery	December 7
Sadie Esh	November 22
Anthony Etter	October 26
Sadie Mae Fisher	November 18
William Forsythe	December 23
Gage Fowler	November 3
Dianne Fox	December 6
Michael Gannon	December 1
Shannon Gearhart	November 18
Kyle Gilliano	November 10
Victoria Gorman	December 14
Robert Griffith	November 2
Matt Gubenski	December 24
Kalob Harriott	December 27
Terri Wagner	November 14
Beth Matous	November 25
Sean McGaughey	November 13
Ericca Meack	December 7
Kyle Michenko	October 22
Sara Murray	October 16
Francesca Paterno	December 31
Zachary Pepper	December 16
Jessica Pochily	November 15
Katrina Ruia	October 17
Mic Sheard	October 29
Rhonda Shinham	December 26
Johnny Supsic	November 18
Mary Kate Zimmerman	November 2



A letter from the President

We have recently welcomed two new members to our Board of Directors- Janice Paterno and Deb Giliano. These two women, along with Desiree Spinney, organized and ran the first annual MACPAD Walk for PKU. Their hard work and dedication allowed us to help fund two very worthwhile research projects that we hope will soon have an impact on our lives. (See story on pages 1 and 2.) For those of you who do not know Janice and Deb, they are two great mothers, both are dental hygienists and are very friendly, giving individuals.

If you have an opportunity to meet them or if you are planning to attend the PKU Walk next year, please make a point to introduce yourselves and welcome Janice and Deb to the MACPAD board of directors.

Judy Griffith, President and mom to 3, 2 with PKU

PA Adult Basic Insurance Program

By Linda Gilbert

Fortunately for us, all through Daniel's childhood there was a program whereby the state of Pennsylvania paid for his formula. That was at a time when insurance companies would not pay for the formula so our health insurance coverage was of no use in obtaining and paying for formula for metabolic birth defects.

When Dan turned 21, things changed. The state no longer covered his formula and he was employed, but had no medical benefits. He was not making enough money to pay for his own formula. Where does he turn now?

He tried obtaining medical assistance only to end up with the Catch-22 routine. He was not making enough to pay

for his formula, but he was making too much to obtain medical assistance to pay for his formula. The only answer would have been to have him stop working and apply for full welfare benefits. This was completely out of the question.

This year, however, things have certainly looked up. Through the encouragement of our PA nutritionists in the PKU clinics, a representative from the state program which handles PKU offered to come in and speak with the nutritionists and ascertain what the major problems are in living with PKU. Among other things, it was mentioned that it is a major problem for people who are working, but have no medical benefits to afford their formula after being on the diet all their lives.

Now there is a program for PA residents who are working a minimum number of hours and who have no medical insurance. Thanks to Joan Kehler, of the Division of Maternal and Child Health Program in PA, the program covered formula from the start.

The PA Adult Basic Program provides PKU formula as well as other medical coverage such as doctor office visits (\$5.00 copay), hospitalization, surgery, emergency room (\$25.00 copay), maternity and newborn care, gynecological and obstetrical care, mammograms, diabetic supplies and oral agents as well as organ transplants and related immunosuppressants.

Being as the plan does not cover prescription items, it was set up that the PKU formula does not come under "prescription items".

They offer a varied list of participating physicians and hospitals throughout the state. The plan is under Independence Blue Cross and Pennsylvania Blue Shield/Caring Foundation. The cost for this program is \$30.00 per month.

This has been a blessing for Dan and others in his situation. Who would ever be able to justify a person being on the PKU diet all of their life, only to have to discontinue it when they became an adult? I would encourage anyone in this situation to contact this program at 1-800-464-5437 to apply. More information on this program, along with qualification and financial guidelines can be found on the Internet at <http://www.insurance.state.pa.us/index.html>

Uncle Henry's Pretzel Bakery

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ALL TINS SUBJECT TO AVAILABILITY

Pennsylvania Women, Infants and Children (WIC) Program Helps PKU Families

If you are pregnant, recently had a baby, or have children under the age of 5, the Pennsylvania WIC Program may be able to help you. WIC is a nutrition program that provides healthy foods, nutrition and breastfeeding information, and referrals to community services. WIC also helps provide formulas for infants and for children and adults who have special health needs, such as PKU.

If you or your child have PKU and are eligible for WIC, the WIC Program will:

- Help pay for your PKU formula. (WIC will reimburse the Pennsylvania Department of Health for the PKU formula that you receive. This allows the Health Department to help more people.)
- Provide other infant formulas, if needed.
- Provide juice, cereal, and Farmers' Market Coupons for fresh fruits and vegetables.
- Provide breast pumps and breastfeeding support.
- Provide referrals to community and health services.
- Provide foods such as milk, cheese, cereal, juice, eggs or formula to other eligible family members.

Many families don't realize they qualify for WIC. WIC income guidelines are listed on the following page:

Families may earn up to (gross income):

Family Size	Monthly	Yearly
1	\$1,366	\$16,391
2	\$1,841	\$22,089
3	\$2,316	\$27,787
4	\$2,791	\$33,485
5	\$3,266	\$39,183
6	\$3,741	\$44,881

(Expected babies are counted in family size)

Foster children, Medical Assistance, Cash Assistance, and Food Stamp clients are income eligible.

To find out more information about WIC in Pennsylvania, call Evelyn Arnold, RD at the Pennsylvania Department of Health WIC Program (717) 783-1289. Or, call 1-800 WIC WINS to find the office nearest to you.

Ener-G Foods Low Protein Bread Mix Pancakes

1 cup Ener-G Low Protein Bread Mix	1 tsp. Baking powder
2 Tbsp. Brown sugar, packed	2 tsp. vegetable oil
2/3-cup water	

Blend together the Low Protein Baking Mix, baking powder and brown sugar. In a separate bowl add oil to water, and then beat in the low Protein mixture. Mix until smooth (batter is quite wet), Pour onto hot griddle and flip once. For variation, sprinkle cinnamon or nutmeg into batter or use apple juice instead of water.



PKULife.com is having a holiday sale! Order PKULife 1.0 software for only \$29.95 (plus shipping) and, for a limited time only, every order of PKULife 1.0 software will be shipped with a FREE mini flip-top personal calculator (while Supplies last. For additional information log on to www.pkulife.com or call 610-983-9939.

Genuardi's Simplifies "Cash Back" Program

It is no longer necessary for you to collect cash register receipt tapes and then forward them to MACPAD. Genuardi's has now teamed up with eScrip, an electronic fundraising program.

All you need to do is to register your Genuardi's club card, once each year, either online at www.escrip.com or by signing up at the customer service counter at your Genuardi's Market. In either case be sure to direct the "cash back" to **Mid-Atlantic Connection for PKU (Group ID Number 149572268)**. Genuardi's will then automatically send their "Cash Back" money to MACPAD through eScrip.com. It will no longer be necessary for you to collect cash register receipts and we will no longer have to tally them and send to Genuardi's to receive the "Cash Back" money.

The money that MACPAD has received through the Genuardi's "Cash Back" program has been very important to the organization. It has helped to allow us to eliminate membership dues and to provide our newsletter to everyone that wants it free of charge. We hope that you will register your Genuardi's club card, ask your friends to do the same, and have the funds directed to Mid-Atlantic Connection for PKU (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!

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For PKU and Allied Disorders, Inc**

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