



A Letter from the President

It has now been two years since we began offering free membership to MACPAD, along with free copies of our newsletters. At first the board was concerned about our ability to continue as an organization without consistent donations. However, we have found tremendous support from many of our members, including donations of both money and of time. It is really rewarding to see all of the effort that our members have put forth to make sure that this organization is a success. We can accomplish a great deal with all of your support!!

If you are interested in donating your time and/or your money to MACPAD, please send your tax-deductible contribution to our Treasurer, Robert Johnstone, who is featured in this issue, at PO Box 6086, Lancaster, PA 17607. If you would like to donate your time, you can email me at info@pkumac.org, or call our Secretary, Sharon Johnstone, at 717-872-7546.

In this day of Internet exchanges, please remember that one of the values of our organization is that we can help each other face-to-face. You can make a friend, share your experiences, and get help in your day-to-day dealing with PKU (or another metabolic disorder), just by reaching out. I hope to talk to you soon.

Judy Griffith, President

New Column

Beginning with our last edition, we are featuring the biographies of our officers and Board of Directors of MACPAD. This time you'll read about the Treasurer and one of our Board members. See page 6.

CONFERENCE 2002 A Success!

On Friday, August 2, 2002, 120 people gathered at the Lantern Lodge in Myerstown, PA to learn and share information and thoughts about metabolic disorders. Dr. Erik Puffenberger discussed and explained cell mutation and genetic research. Chris Prout and family talked about the adaptations that can be made to help a PKU person succeed and Fran Rohr told everyone how diet can be for life and factors for making it work. During the motivational banquet, Bill Crosky told of his inspirational life and how PKU had really made him the man he is.

We sponsored three small discussion groups who met privately and talked about feeding toddlers; sports and social events and PKU and one group even worked on a new pocket phe book. Ken Barton, Laurie Graver and Anne Starr led these groups. Free babysitting was provided, during the sessions, by the senior childcare class at ELCO High School. But, everyone agrees that the best thing was meeting old friends and making new ones.



Ning Lu and Cindy Hoover exchange ideas.

The Friday evening low protein/regular buffet was a first for MACPAD! The low protein food suppliers donated products and monies to supplement the banquet.

MACPAD provided additional financial support. The Lantern Lodge prepared and served salad, spaghetti, rolls, stir-fried veggies and sautéed mushrooms. We were treated to strawberries with whipped topping and cookies for dessert. Thanks to everyone who worked on the conference and to everyone who attended!

zoo. Some enjoyed purchasing MACPAD t-shirts or gathering literature prepared by our suppliers. All enjoyed the camaraderie!



Nellie Lohmiller and Emily Myers listen to Fran Rohr.



Terry Haney showing off his new MACPAD T-shirt

***** For anyone that would like a video of the morning and afternoon speakers, they are available for \$10.00. Send your check to MACPAD and we will forward the order to the videographer. First copies will be available around September 10,

Everyone waited until the time came for the announcement of the winner of the handmade quilt, a blue, green, yellow and white masterpiece. The winner was JoAnn Guinan, grandmother of Patrick Guinan, of Drexel Hill. JoAnn said she “was so thrilled” when she was told that she had won. Second place was captured by Carole Tims of Runnemead, NJ. Carole won a handcrafted pair of silver earrings donated by Reflections in Silver. Carole said “It’s the first time I ever won anything!” Zachary Pepper won the “handprint quilt”, donated and made by Lynn Trump to honor those with PKU.

PICNIC 2002

Saturday, August 3, 2002 was hot and humid but it didn't dampen the fun of the over 200 guests at the Weavers' Farm in Denver, PA. Featuring a low protein buffet and the usual fun activities, the day was filled with laughter. We had hayrides, a piñata



Getting ready for the hayride



Zachary and his quilt

an airplane candy drop and the baby animals in a petting



PKU AND BLOOD WORK

By Mrs. Amy Hughes

We are excited to announce the opening of a Cambrooke Foods' Canadian Distribution Center. Canadian customers can order using our toll-free number or web site and have products shipped directly to them from a Canadian Distribution Center.

Cambrooke Foods has also been busy lately working to bring more delicious low protein foods to your family's table. Pasta lovers will want to try our new Spaghetti and Short Grain Rice. Both are versatile products and the kids love them. New and improved cream cheese varieties will soon be available for you to try.

We have changed our packaging due to customer demand so that you can purchase smaller amounts of most items, yet still save money by ordering in bulk. For example, all of our delicious Bagels and Energy Bars can now be purchased in sleeves of 5 bagels or bars. More convenient 2-pound packages of Shredded Cheddar and Mozzarella are now available as well as 2-pack sizes of Sliced Cheese. These products can be ordered at reduced prices if you buy 6 or more individual packages of the same product. We do ask that you order a minimum of \$50.00 in "cold ship" products when you place your order.

Check out 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.

Our friendly staff is working to make the ordering process easier. You can order 24/7 through our call center, toll-free at (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.

Our sympathies to our friends at Ener-G Foods for the loss of their founder and chairman, Sam Wylde Sr. Mr Wylde died on August 14, 2002 following a brief illness.

This article is respectfully dedicated to those moms who do the blood work, and their PKU children.

This story begins with my daughter who has classical PKU. When my girl was around two and a half years old, or old enough to speak in full sentences. I was preparing to do her blood work and I knelt down to do her finger stick, and she looked at me and said, "mommy please don't hurt me", well my heart just wanted to explode, and the tears welled up in my eyes, I was ready to ball, while in my mind I said to myself, if she sees me cry that would make the situation much worse, so I swallowed my tears and looked at my daughter and said "honey it's not me hurting you it's this little blue thing (the lancet)". My sweet daughter got the concept of what I said and fully understood. From that day on she never asked me to not hurt her.

Well one day I was reading, and I'm not sure now if someone told me this, but it was to give a child the feeling that they have power over a situation, so I took that to heart. I was getting ready to do blood work again, and I asked my girl Kim which hand she wanted me to do the blood work on, and which finger the middle or ring finger. Now my daughter is almost six years old and we do blood work the same way with one exception, I added to that, now when we do blood work I tell her to close her eyes and say something like goobely goobely go, really loud, and by the time she's done yelling that the finger stick is done. When you prepare to do blood work you can have your child warming his/her hands in warm water at the sink, you can even make that a game, if the child is a toddler you can have them do it in a large pot with items that sink to the bottom, even small toys. When my child was even smaller we used to warm her feet in the sink, and let her splash and play, (we even have a video of this). When we are finished I have her hold a gauze pad on the puncture, until I have the band-aid at her finger. (She feels like she is a big help).

For the parents that are new to this, it is helpful when both **parents do the blood work together**. In the beginning this was difficult for my husband, he thought he was responsible for giving my child the PKU, so I told him that, that kind of thinking was making it more stressful for all involved. We had a long talk about our feelings. If you need to do this, do it now, if you feel you need help, most of the PKU clinics have a social worker, you can talk it over with them.

While my child and I do blood work, I show her how well we filled in the dots on the Guthrie. I have involved my child in every aspect of the management of PKU. When blood work results come back I tell her what the level is and whether it is good, or a little high, when it is good we do a (high five) and she yells yea! When it is a little high I tell her we just have to watch the diet a little more closely. I always tell my daughter that she is the most courageous little girl I know, and that maybe someday she will become a doctor and cure PKU, and no little children will ever have to do finger sticks. I always encourage her. There are a lot of helpful tips in the back of the low protein cookery cookbook, for PKU.

When my husband and myself were first informed of the PKU and in the hospital, it was difficult to grasp the whole thing until the third day. I then went outside for fresh air, and a woman recognized my name tag as a parent of a sick child, we began talking and she asked why I was there, and I explained, when I asked her why she was there she told me that she was waiting for her nine year old daughter to die, (she had a brain tumor). Well, I'll tell you, I felt very lucky I had a child with PKU and that it was controllable.

I have always said, and always believe, that God would not have given me a child with PKU, if he had not trusted me enough to take care of and be able to handle the very detailed work it takes to do this diet. I do believe he knows who can and cannot handle this type of disorder or any other, he entrusts us with these very special children.

Here is a handy guide to remember when doing blood work:

- 1.) Educate your child early, on PKU
- 2.) Give the child the feeling of power
- 3.) Always involve the child in the process
- 4.) While warming hands under water, make it fun
- 5.) Encourage and praise your child
- 6.) Always tell your child the Guthrie results. (It makes them feel like they accomplished something great)
- 7.) Never yell at the child, see it from their point of view

From a very grateful mom, with a normal and healthy daughter.

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.

For over 38 years our commitment to purity, quality and innovative products has set the standard for others to follow.

Contact Us:

Ener-G Foods, Inc. P.O. Box 84487 Seattle, WA 98124-5787

Phone:

(206) 767-6660 Toll-FREE 1-800-331-5222

FAX: (206) 764-3398

What a great snack, these pretzels are our most popular! They truly have a wonderful rich, crisp, buttery flavor. Made for special people with special diets, but these ones anyone will love. Some great tips..... Melt cheeses and dip them! Yum!! Or how about our low-protein chocolate. Melt the bars drop the pretzels in and have your own special low-protein chocolate covered pretzels.

Enjoy.....

Ener-G Foods



www.ener-g.com

Crisp Pretzels



Ingredients: *Corn starch, palm oil, modified corn starch, soy flour, sugar, salt, baking powder (ammonium bicarbonate, sodium bicarbonate), lecithin from rapeseed from rapeseed(emulsifier), sodium carboxymethylcellulose, yeast. KOSHER (Circle U)*

[Click to enlarge](#)



Happy Birthday To Our MACPAD Friends!

Nutrifacts:

Free of: Wheat, gluten, dairy, egg, nuts

Phe amounts:

per 100g of product:...139.00

per serving:...41.70

Our Phenylalanine amounts are obtained by three methods:

- 1) outside laboratory testing contracted by Ener-G Foods, Inc.;
- 2) computations based on a nationally recognized database; and
- 3) for products manufactured by other companies, the phenylalanine amounts may be supplied by that manufacturer.

It is important to remember that true Phenylalanine amounts may vary from those amounts listed because of several factors, including baking or cooking variations.

All feedback is appreciated.
Ener-G Foods, Inc.

Todd Atkinson	July 22
Eric Johnson	August 16
Brian Noll	August 23
Melinda Fouse	July 15
Kenny Barton	July 23
Jessica Martinez	September 20
Deidra Kline	August 19
Amy Shuler	August 23
Michael Flood	August 2
Zachary Allwein	July 7
Kimberly Hughes	September 13
Jack Robertson	September 28
Jacob Smith	July 16
Shane Shuler	August 4
Sophia Kvam	July 21
Patrick Guinan	August 15
Samantha Pape	September 5
Allyson Deihl	September 8
Ryan Purcell	September 10
Mary Buchowski	September 19
Philip Teasdale	August 21
John Spese	September 13
David Wagner	July 16
Sarah Foster	August 18
Jennifer Kirkdoffer	August 21
Alice Wells	September 13
Joseph Hoover	August 9
Kim McDowell	July 27
Steven Droogan	September 4
Terry Haney	July 4
Charley Griffith	July 20
Cathryne Wheeler	August 11
Kacey Lloyd	September 7
Ethan Guyer	August 16
Bayley Clifford	September 6
Jessica Schlotter	August 1
Hunter Kane	July 13
Corey Kirby	July 17
Burg Ning Liu	July 21
Alexander Stein	August 2
Logan Royer	August 18
Taylor Chandler	September 24
Mark Boiko	September 25
Allison Zimmerman	August 8

IT'S ITALIAN! WE WANT TO OFFER YOU A WIDE VARIETY OF LOW -PROTEIN PASTA OPTIONS, THESE HAVE RECEIVED RAVE REVIEWS.

[Low Protein/Gluten Free Large Shells](#)

LOW PROTEIN

[Low Protein/Gluten Free Lasagna](#)

LOW PROTEIN

[Low Protein/Gluten Free Macaroni](#)

LOW PROTEIN

[Low Protein/Gluten Free Small Shells](#)

LOW PROTEIN

[Low Protein/Gluten Free Spaghetti](#)

Meet A Board Member and Picnic Chairperson



I was elected to the MACPAD Board in January 2001. I am the Aunt to Ken Barton Jr., a PKU child, and sister to Ken Barton Sr. also on our Board, as Vice President.

I was born and reared in the Lancaster area and attended J.P. McCaskey High School and Millersville University, majoring in Spanish. I have a variety of interests including traveling, reading, meeting new people, and spending time with Ken Jr. and his sister Kara.

My favorite place is Southern California (especially the San Diego area); in fact, I lived there for a time in 1987. One of my favorite subjects is biology and I enjoy reading as much as I can on the research into PKU and Allied Disorders. I have chaired our MACPAD Picnic Committee, along with Lynn Trump for the past two years.

I have held a variety of positions, most recently spending seven years as a Customer Service/Sales person for CNG, a worldwide dealer in Ancient coins. "It has been the most interesting and challenging position I have done. I talked with customers worldwide and many of the customers became good friends as well as customers. Our company started selling on the Internet in 1998 and it quickly grew to be our primary source for business". September 11th and the economy greatly affected the business. I am looking

forward to starting a new position as a Bi-lingual Service Representative with the Social Security Administration in September. I will also be taking an Ancient History class at Millersville University.

Meet The MACPAD Treasurer



My name is Bob Johnstone. I am currently the Treasurer of MACPAD. I got this job after my daughters founded this organization and needed someone to raise the money to pay the expenses involved. I managed to find an anonymous donor to contribute the initial \$500 to pay for legal ads, website registration, and other start-up costs. Since I had done so well, I was asked to become treasurer of the new organization.

I retired in 1995 after 32 years with General Waterworks Corp. I had held a number of jobs with GWC in a number of locations. I began as a District Engineer in Altoona, PA and ended as Vice President Of Operations in King of Prussia, PA. In between, I held several engineering and several management positions in Philadelphia, PA and Newtown, CT.

My wife, Sharon and I have been married 39 years and have two daughters, Laura and Judy. We have four grandchildren - Nick, Charley, Bobby, and Kyla. Charley and Bobby have PKU.

After Charley was born with PKU in 1997, Laura, Judy and I attended a Conference put on by the New England Connection for PKU and Allied Disorders. I learned a lot about PKU and the other disorders but most of all I

learned how important it is for the parents and kids affected with PKU to have the support of such a group. So when my daughters decided to form a similar group in our area, I was happy to support them.

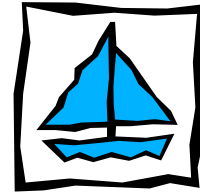
After they created the not for profit corporation that MACPAD is, we worked to gain acknowledgment from the IRS that MACPAD is a tax exempt, charitable organization under section 501(C)(3) of the federal income tax code. The IRS granted us this status, so all donations to MACPAD are tax deductible by the donor for federal income tax purposes.

MACPAD has become an amazing organization through the efforts of a large number of people. We have eliminated membership dues. We maintain a website that has seen use from around the world. We hold an annual picnic. We have sponsored two regional conferences. We have sponsored a cooking demonstration. We sponsored the first "Walk" for PKU research. We published a cookbook of recipes from PKU families and have sold more than 700 copies. We publish a quarterly newsletter and provide it free to our members. We helped organize a PKU cruise from New York City to Nova Scotia.

MACPAD has no paid employees. Volunteers do all of our work. Our funding comes from three sources - donations, annual quilt raffle, and cookbook sales. Donations come in several forms. We have a number of members who regularly send us their receipts from Genuardi's Markets. We can turn these in and receive 1% of their value as a donation from Genuardi's. We also receive donations from people who designate MACPAD for their United Way donations. The low protein food suppliers and other vendors who provide products or services to people with metabolic disorders have been very generous in supporting MACPAD through donations of their products, their time and their money. MACPAD also receives direct donations from individuals. All of the donations that we received from the PKU "Walk" or that are designated for research are held and used only to fund research.

Each year we raffle a hand quilted Lancaster County quilt. The proceeds of this raffle help to pay for our Annual Picnic. The sale of each of our cookbooks provides a couple of dollars to meet the other expenses of the organization.

All in all, a great number of people contribute to the success of MACPAD by donating their time, their talent, or their treasure. I am honored to be able to serve them by being their Treasurer.



Memories From The PKU Cruise

This year we had a great opportunity to cruise on Carnival Triumph with a group of PKU Families. We had a blast! First we get to New York and see this huge ship that was over whelming, Then we board and find that we are in a first class hotel on water. After unpacking and a quick tour we met with the other families. Some came from the West and some were local, we came from New Jersey, and all were exchanging ideas and asking questions. The children ranged in ages from 1-23, our sons Greg (PKU) and Richard were reluctant to interact, but some seemed to become instant friends. The first night we ate in the dining room, where the children with PKU were served low protein food, all arranged by Pat Byrne. The food was good, everybody got to chat and get to know each other. There were other areas on the ship to eat, but the low protein food was only served in the dining room. After, dinner everyone went on their way with their families and we called it a night. I could not believe how well we slept, I thought we would all get hit with seasickness, but really you don't feel the ship move at all.

Friday, we woke up to dense fog, you could not see anything, but everyone still had fun. We arrived in Halifax, Nova Scotia, Canada on Saturday. There were tours offered on the ship, and we chose to wander the Waterfront. It was cold and misty, but we still had a great time. We took the HARBOUR HOPPER with 2 other families we met, it was very informative, and we wished we had more time to see more sights. On the way back to New York, the weather improved and the kids did get in the pool, they loved the water moving in the pool making waves, because of the movement of the ship. We went to a Dance Show, a Comedy Show, played a lot of bingo and enjoyed a few activities like the Newlywed Game or What's in your Bag. They all put smiles on your face. I would like to thank Pat Byrne and her family who played a big role in making this trip a success. I would also like to encourage you to jump in on the fun the next time a cruise comes up.

Bonnie Reynolds



dp Low Protein Baking Mix

For use in special diets requiring control of protein, sodium, potassium or phenylalanine. Use these recipes to make delicious breads, coffee cakes, muffins, cookies, cakes, desserts, croutons and main dishes.

To Measure: Fluff with fork; gently spoon into measuring cup and level with knife. Do not tap or press down.

To use dp Low Protein Baking Mix in your favorite recipes:
First, consult your dietitian about allowed foods (and their quantities), then follow these tips:

1. Use more baking mix than the flour it replaces.
(About $1\frac{1}{3}$ times for muffins and cakes, approximately twice as much for cookies.)
2. Reduce the amount of shortening, butter or margarine by about 1 tablespoon for each cup of baking mix used.
3. Add liquid slowly by tablespoons until desired consistency is reached.
In most cases, water can be substituted for milk.
4. Our recipes and calculated nutritional values are based on the use of medium size eggs, unsalted margarine and low sodium baking powder.
1 medium egg = 10 teaspoons (1 large egg = 12 teaspoons)
One package yeast = 3 teaspoons

White Bread

1 package active dry yeast	4½ cups
¼ teaspoon sugar	dp Low Protein Baking Mix (500 grams)
1¾ cups warm water (105° to 115°)	1½ teaspoon salt, if permitted

Generously grease loaf pan, 9 x 5 x 3 inches. Place $1\frac{3}{4}$ cups warm water in large mixer bowl. Add sugar and yeast and let stand 5 minutes. Add baking mix (and salt). Mix on low speed about 15 seconds. Scrape bowl and beater. Mix on medium speed about 30 seconds. Batter will be thick. **DO NOT ADD WATER.** Pour batter into loaf pan. Cover with paper towel and let rise in warm place (100°) until batter is 1-1½ inches ABOVE TOP EDGE of pan (1-1½ hrs.). Bake in preheated 425°F oven for 30 minutes. Remove from pan immediately. Cool before slicing. For a softer crust, brush top while warm with softened shortening or seal completely cooled loaf in a plastic bag for several hours or overnight.

One loaf: eighteen 1/2 inch slices

Per serving 1 slice: 120 calories, 0.26 gm protein, 23 gm carbohydrates, 15 (0.7) mg sodium, 15 (0.4) mg potassium, 11 mg phenylalanine

Storage: All baked foods can be stored in covered containers in the refrigerator for 3 to 4 days. For longer storage, keep in freezer. For freezing, wrap products tightly with freezer-weight paper and seal with freezer tape. Bread may be sliced before being frozen. Label and date. Cookies, breads and cakes may be kept frozen for at least 30 days



1248 Sussex Turnpike, Unit C-2 • Randolph, NJ 07869
email: info@dietspec.com • 1-888-640-2800 • Fax 973-895-3742

Amish form clinic to treat disorders:

Ohio doctor has Strasburg mentor.

By Francis X. Clines

Copyright © 2002 The New York Times Company. Reprinted by permission.

Burton, Ohio- "We've been waiting 16 years for an answer" said Mark Kauffman, an Amish farmer whose four profoundly handicapped children thrashed spasmodically in wheelchairs and a crib before the watchful gaze of the visiting physician.

As Dr. Heng Wang tended to his helpless patients, their mother, Esther Kauffman, hovered lovingly, translating the sudden cackle of one son as a cry of joy at the visit.

"We've gone through so many things that at this point we don't let our hopes get too high", said the mother, looking to the doctor.

The frequent house calls of Wang to the picturesque Kauffman farm's gravely incapacitated children mark a singular moment in the quiet history of the Old Order Amish here in northeast Ohio.

For Wang is the director of a new research clinic that the Amish have organized to deal with the myriad of hereditary disorders that have haunted children in close-knit Amish and Mennonite communities for years, often with fatal results.

Inspired by recent medical breakthroughs pioneered among Mennonite and Amish children in Lancaster County, the new Das Deutsch Center for Special Needs Children in nearby Middlefield does not have a permanent home yet, but Wang is already off on his rounds.

"We have no time to lose," said Wang amid farmland visits that eventually will take in at least 250 children already identified as suffering mental and physical handicaps among a population of 45,000 Amish.

While the Amish are 12 percent of the local population, their children represent close to half of the area's most severe cases of mental retardation.

The nonprofit center will specialize in deciphering and treating dozens of obscure genetic and biochemical disorders the children suffer. Many of these are still unnamed but considered the result of the "founder effect"- a reference to genetic disorders that become unusually common in an insular population descended, like the Amish, from a small group of progenitors.

For years, affected Amish children who seemed healthy at birth soon suffered brain damage and other forms of retardation. But the Amish here are intent on exploiting some promising diagnostic and treatment innovations proven in a decade of care and research at the Amish Clinic for Special Children in Lancaster County.

A classic brain disorder known as maple syrup disease (because of the sweet odor of a victim's urine) went untreated 20 years ago as a mystery scourge of the Amish. But now, traced to a particular enzyme deficiency, it can be routinely diagnosed and controlled like diabetes, said Dr. Holmes Morton, medical director of the Strasburg clinic.

Similarly, a devastating disorder called glutaric aciduria was finally traced to an amino acid problem, with a treatment devised to considerably lessen the risks of brain damage. While the causes vary widely, the Strasburg treatments emphasize that routine childhood disorders like strep throat can trigger hidden genetic problems- a liver enzyme deficiency, for example with brain-damaging toxins.

"It may be too late for us" said Kauffman, gazing upon his children who suffer from severe and likely irreversible damage in which the oldest, Nancy, 16, can not see or feed or dress herself or respond to communication.

"But if we can help others with this center, we'll gladly do that," the father said as Wang examined Nancy, Daniel, 14, David, 11 and Andrew, 5.

As he worked, the four variously lolled inertly, vocalized wildly and were racked with seizures. Their slender, crabbed physiques made them look half their ages. Previous doctors had ruled out genetic problems, according to the Kauffmans, who began investigating the special clinic approach after Andrew was born.

At the age of 40, Kauffman farms and makes furniture to support his family and pay all it's medical bills. Like other Amish, he believes in quiet personal charity for problems but not in medical insurance or government aid.

Described by one friend as a painfully taciturn man, Kauffman nevertheless came forward to help found the center on behalf of what he calls "the blessings"-his children and those of other Amish as well as non-Amish groups with comparable metabolic and genetic disorders in other parts of the world that the Strasburg clinic has also been treating.

This area's 72 Amish district bishops quickly blessed the appeal to modern science as in tune with their plain traditions. In the last two years, they raised \$700,000 from the faithful-farmers and factory workers-toward the

\$1.8 million center.

Traditionally, the “Plain People”- Amish and Mennonite descendants of 18th century German and Swiss Anabaptists- have shunned many modern inventions and married among themselves to protect their faith-driven way of life. The Amish, like other close ethnic groups around the world, suffer high rates of inherited disorders because of the recessive genes passed through generations. Distantly related members marry and increase the odds of being unknowing carriers of the disorders.

“What’s so terrifying about this is the apparent increase of frequency,” said Tom Stone, the president of Das Deutsch’s board of directors, describing the community’s growing awareness of how recessive genes can finally strike.

“Even if a family doesn’t have affected children, they know what may be in store for the grandchildren”, said Stone, a local non-Amish school principal who is the area’s expert in special education needs.

Research on the Kauffmans disclosed that the father’s generation of family members includes two cases of founder-effect disorders, while the grandparent’s generation has only one. But the newest generation has 9 out of 21 who are handicapped, including Mark and Esther’s brood, who require long days of care for every basic need. Apparently normal at birth, the children quickly degenerated in the first year, with some sort of toxic syndrome expected.

In great urgency. the Das Deutsch clinic saw Wang off on his rounds this month. His program focused in Holmes and Geauga counties, is modeled on Morton’s clinic in Strasburg, the first center for Amish founder-effect disorders, created in 1989.

“He is my mentor,” said Wang, a 39-year-old pediatrician and biochemist. Who spent time with Morton studying his techniques.

Morton has patiently weeded through separate disorders and devised special diagnostic and treatment programs. These emphasize family education, infant screening and high alert to routine sicknesses.

“Dr. Morton has identified more than 80 genetic disorders,” Wang noted “About one-third of the diseases, if diagnosed early, are treatable and can lead these kids close to normal lives,” Wang said, emphasizing tireless

scrutiny in preventing brain damage and death.

Morton, whose clinic treats close to 600 children, said early diagnosis and treatment will head off significant damage in a majority of cases. About one in five with genetic syndromes remain untreatable, he said.

“But 75% are treatable and of those, one-third are highly treatable”, he said.

“It’s very instructive to take care of these children,” Morton said.”They become your teachers.”

The two clinics will not necessarily be similar in their caseloads’ genetic tracings. For while 200 Amish settled in this area in about 1800, the 20,000 Amish and Mennonite now in the Lancaster area served by Morton had different origins, founded by 12 families 300 years ago.

The Amish here have received support beyond their rural target zone from the Cleveland Foundation, University Hospitals and the John and Sue Turben Foundation.

What the general public might not realize is that the Amish have participated in modern genetic studies since the 1950’s, noted Caroline S. Morton, the executive director of the Strasburg clinic. Beyond Mennonites and Amish, children from as far as Asia and Africa make up about 15% of the clinic’s caseload.

“We follow kids all over the world,” said Mrs. Morton, the wife of the medical director.

That is a clear comfort for Kauffman as he serves on the new center’s board and must concede a cure will likely elude his children.

“If anything good comes out of all this, we need to give God all honor”, he emphasized as Wang headed out on his rounds.

Clinic For Special Children Auctions

Blair County/Morrison Cove- September 7

Lancaster County/Leola, PA September 21

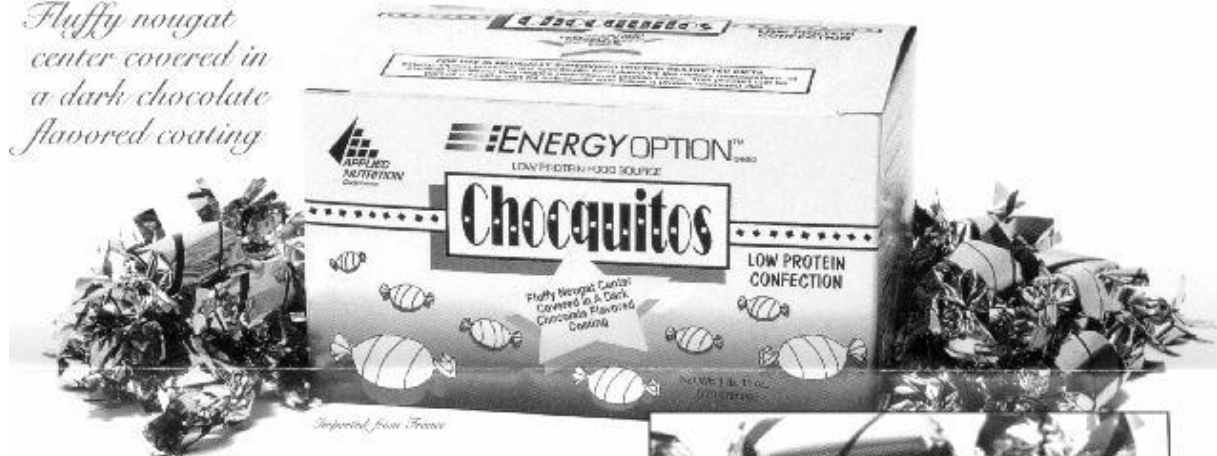
Call 717-872-7546 for more information.

LOW PROTEIN *Confection*



CHOCOQUITOS

Fluffy nougat center covered in a dark chocolate flavored coating



Nutrition Facts

Serving Size: 1 piece (14g)
Servings Per Container: about 60

Amount Per Serving		% Daily Value*
Calories 60	Calories from Fat 15	
Total Fat 1.5g		2%
Saturated Fat 0.5g		3%
Sodium 0mg		0%
Total Carbohydrate 11g		4%
Sugars 11g		
Protein less than 1 gram		

Not a significant source of cholesterol, dietary fiber, vitamin A, vitamin C, calcium, and iron.

*Percent Daily Values are based on 2,000 calorie diet.

Ingredients: Sugar, cocoa paste, cocoa butter, corn syrup solids, water, lactose, hydrogenated vegetable oil (palm and soy), corn starch, condensed skim milk, sorbitol, cocoa powder, mono- and di-glycerides, soy lecithin, vanillin.

The following information is provided for those individuals, who on the advice of a physician, are controlling their total dietary intake on certain critical nutrients.

Serving Size: 14g (1 piece)	
Protein	0.35g
Phenylalanine	12.5mg
Isoleucine	9.5mg
Leucine	17.5mg
Valine	14.5mg
Potassium	18.0mg
Phosphorus	8.5mg

For use in Medically Supervised Protein Restricted Diets.

Energy Option™ products are specifically formulated for the dietary management of medical conditions that require restriction of protein intake. This product can be part of a healthy diet for individuals who follow a protein restricted diet.

Dietary Exchange

One Chocquito = One PKU Diet Exchange
(Each exchange = 15 mg of phenylalanine)
Suitable for wheat-free diets

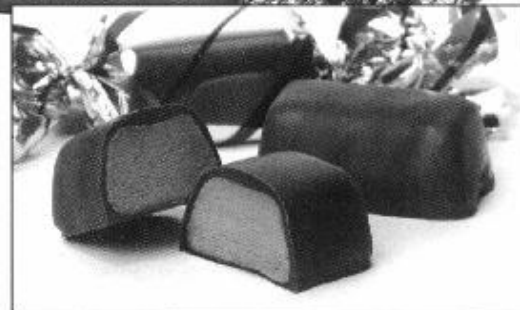
Specifications

Product Code: 8901
Box Weight: 1lb 1oz (770 grams)
Box Contents: Approx 60 individually wrapped pieces

Store in a cool dry place

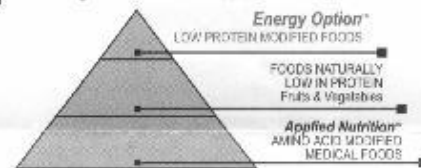
Ordering Information

Call **1 (800) 605-0410**
to place an order or request an order form.
Visa and Mastercard accepted.



The Low Protein Diet Food Pyramid

Using Medical Foods to Supply Amino Acid Protein*



*The information is provided for those individuals who, on the advice of a physician, are controlling their total dietary intake on certain critical nutrients.

Random Reflections

Remembering not so long ago....the August MACPAD Conference was a special blessing for my husband and me. We extend our gratitude to the MACPAD team!

Our son Joe was born in August of 1980 with PKU. We didn't have a conference to attend until the following summer. It was a very long year. The Internet was not in existence. We were not made aware of any national PKU newsletters. We were never introduced to any other families with PKU until Joe was 6 months old; and then only to see them as we awaited our appointment at the clinic. Our only connection was a weekly phone call from his dietitian, notifying us of his blood level and advising of alterations of Phe intake.

The first year of his life was like taking an exam on a daily basis. The problem was we did not know the test results for an entire week! The diligence of implementing "this diet" would greatly affect the future mental capabilities of this new life entrusted to us. It was an overwhelming responsibility, and one that I know I was only able to embrace by God's grace.

Joe's 22nd birthday was yesterday. As I reflect on all that has been accomplished through research and access to information in these years, it is awesome! Babies born to PKU families today can have a much greater level of confidence as they begin their work as parents.

Diet for Life was always presented to Joe like the elusive butterflies that he loved to try to catch as a little boy---"just continue the diet another year Joe", and the following clinic visit the same presentation---"research shows it would be best if you stayed "on diet" another year!" Joe was a bright child, and knew by the age of 8 or younger that this "diet" was for keeps in the mind of his doctor....and probably it would be Mom and Dad's idea as well. He was right. If medical research in the beginning of his new life indicated "diet for life", it would have been viewed by us as a medical mandate. But medical mandates, as we all know, take time and research dollars. With the small PKU population, these absolutes take time. We are so thankful that we as a family were obedient .

I fully appreciate the struggles and moments of heartaches that parents experience, raising a PKU child to embrace "the diet for life" concept. After all, it is difficult for all of us to try to do "the right thing" as it relates to our own health. Knowing that we wanted the best for our son and knowing so little about PKU, we trusted the experts. I would

encourage those of us in this PKU World to be thankful for the healthy bodies these individuals gain by "diet for life", and we as members of their family come to be healthier as well....an added bonus!

With confidence, we know that as these children become adults, their bodies will be healthier than the general population; and for that we need to be most grateful.

As families use the many resources available to gain knowledge, support and suggestions for coping during the "low points", your child will grow up to be a happy, healthy, self-reliant adult! The "low points" become a vivid memory, but a wonderful reminder of how much your child grew as an individual in ways that you would have never expected as a result of following "the diet".

The things in life that "stretch" our children the most are those things that we least expect, ones that we would never "give" to our children (in most cases, we would strive to protect them from or deny them). PKU was like that for us in the early years. But 22 years later, we truly are thankful for all the many ways it has molded our son to be the happy healthy man that he is today!

If a child lives with criticism, He learns to condemn.
If a child lives with hostility, He learns to fight.
If a child lives with ridicule. He learns to be shy.
If a child lives with shame. He learns to feel guilty.
If a child lives with encouragement. He learns to be confident
If a child lives with praise. He learns to appreciate.
If a child lives with fairness. He learns justice.
If a child lives with security. He learns to have faith.
If a child lives with approval. He learns to like himself.
If a child lives with acceptance and friendship.
He learns to find love in the world.

Cindy Hoover

Curried green tomatoes

Here's a quick and easy dish that serves one. Use 2 green tomatoes, small onion, butter and curry powder to season. Sauté the onion in butter, add curry and tomatoes and fry until cooked.

Grandmas Corner



Dear Grandma,

My son/daughter is starting kindergarten soon, and I was wondering if you could give me some ideas as what to pack for lunches and snacks?

Answer:

Dear Mom,

The first thing to be considered when planning your child's diet is how many phes he/she is allowed. I am lucky in that my grandchildren have a mild form of pku and are allowed more than some children. For school lunches, my daughter will pack the things that my granddaughter loves most to be sure that she eats everything. She loves peanut butter (lo pro of course) and jelly sandwiches and also enjoys lettuce, tomato and cheese (whitehall brand cheese) sandwiches. There are now some new options to sandwiches. We recently purchased the tortilla/wrap maker from Cambrooke foods and it works really well. We make the wraps and fill them with anything you would put on a sandwich and just roll it up and cut it into finger foods. The wraps are good also with just jelly in them, or the cream cheese from Cambrooke foods. We have also used the recipe for mushroom burgers and used the mixture cooked and crumbled into the wraps with a little taco sauce for seasoning. Salads are also a good choice for school lunches. My granddaughter is also allowed to order just a salad or french fries for lunch. We are lucky in that there is another child with pku in her school, so the school is very cooperative with their diets.

For snacks, my granddaughter's school prefers they have healthy foods, not sweets. She loves all fresh fruits and homemade puddings. We also make her celery sticks or carrot sticks with ranch dressing to dip them into. For those that are allowed to have sweets at school, we would use the rule if it contains less than one gram of protein it is ok. From talking with a few other mothers, dunkaroos (cookies & frosting) are a good snack. Any of the low protein cookies that you make or buy are good. Candies such as Gushers, the chewy lifesavers are a favorite as are Sprees and Starburst. We save small containers with lids for snacks like

pudding, yogurt (lo pro) and ice cream when there is a birthday party at school. Columbo yogurt comes in a nice cup with a lid that has a spoon built into it. The children can't have the yogurt, but the cup with the spoon built in is great to put their snacks in for school.

School lunches and snack need not be something scary. The only thing we do try to do is to make my granddaughter's lunch look as much like the other childrens' lunches as possible.

Hope this helps,

Grandma



You can now order MACPAD items online at www.PKULife.com using a credit card!

We have made special arrangements for you to order **MACPAD T-Shirts** and our cookbook - **Creative Family Cooking - Recipes and Menu Planning for PKU** online. Just visit www.pkumac.org/OnlineStore.htm. This is a great, fast, easy way to order from MACPAD. Items ordered are usually shipped in 2-3 business days.

Creative Family Cooking - Recipes and Menu Planning for PKU is the newest cookbook for the PKU Community has sold over 700 copies to individuals in 44 states and 6 provinces of Canada! **MACPAD T-Shirts** are light gray with the MACPAD logo on the front. They are also machine washable 98% cotton and preshrunk.

Editor's 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.

**The Dietary Shoppe, Inc.
184A East Evergreen Avenue
Philadelphia, PA 19118
215-242-5302**

NEW PRODUCTS AVAILABLE

**Aproten Biscotti
Cerrone Waffle Cones
DS Herb & Garlic Ziti**

Order by Phone or Website or Stop by.

Hours: Tuesday–Saturday 10-5:30 pm

Gift Baskets & Gift Certificates Available.

Visit our new website <http://dietaryshoppe.com>



Address: P.O. Box 6086
Lancaster PA 17607
Phone: 717-872-7546
Email: Info@pkumac.org
Website: www.pkumac.org

Newsletter Contributors

Judy Griffith, Carol Barton, Sharon Johnstone,
Laura Assayag, Amy Hughes, Bonnie
Reynolds, Robert Johnstone, Cindy Hoover
and Peg Lunt

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**

Officers

President

Judith Griffith

Vice President

Ken Barton

Secretary

Sharon Johnstone

Treasurer

Robert Johnstone

Board of Directors

Carol Barton

Lynn Trump

Christy Schulze

Laura Assayag

Janice Paterno

Deb Gilliano

Honorary Board Members

Karen Blackbird

Linda Tonyes

Ann Starr