



A Message From the MACPAD President

As I write this, we have just returned from our 14th annual PKU Picnic. The picnic was started by the Hershey Medical Center metabolic clinic and three years ago MACPAD joined forces with them to continue the tradition. The picnic was quite an interesting and fun-filled event (you can read more about the picnic on pages 2 3 and 9).

I believe that the best part of the annual picnic is the opportunity for the children to meet and interact with other children with PKU, who are living with similar dietary restrictions and who often deal with many of the same social issues. It is also a rare treat to be able to say to your child "you can eat anything you want today!"

One thing that I noticed at the picnic is that much of our strength (and probably one of the major factors in our organization's success) comes from the extended families of the individuals with PKU. Our picnic was organized and made possible by 3 grandparents and one aunt of children with PKU. We applaud their dedication to helping their families (and all of our families) and to making these events possible, when many of the

parents of children with PKU (like me) and adults with PKU are so busy dealing with our every day lives and the added stresses of living with a metabolic disorder that for many of us it is difficult to find time for these things! It also makes me think that there are probably many other grandparents, aunts, uncles and siblings out there who may have the time and energy to help. We welcome you! Please contact us and let us know how you would like to help.

I would like to extend my sincere appreciation to Carol Barton, aunt of Kenny Barton, Lynn Trump, grandmother of Logan Royer and Bob and Sharon Johnstone, grandparents of my two sons Charley and Bobby for their hard work and dedication to making this year's picnic a success!

Please make plans to attend our next picnic scheduled for August 3, 2002. We will also be holding a conference on the day before the picnic – August 2. We will be sending out more details soon, so mark your calendars. We hope to see you there!!

Judy Griffith
Mother of 3 boys, 2 with PKU

Conference 2002!

Plans are underway for the next MACPAD conference, Friday August 2, 2002, the day before our annual picnic. More details will follow in the next newsletter. The conference is being planned at The Lantern Lodge in Myerstown, PA, a lovely quiet country setting only 35 minutes from the picnic location.

Congratulations to the Winners!



Kim Robertson and son, Jack
Our second place winners

Of the Annual Raffle!

First Prize- a queen size handmade Amish quilt- **Faith Saldi**, friend of MACPAD.

Second Prize- a handmade wall hanging (created by Board of Director member, Lynn Trump)- **Kim Robertson**, PKU mom

Third Prize – a gift basket of food from The Dietary Specialties Shoppe Inc. – **Allison Royer**, PKU mom

Fourth Prize- a complimentary copy of the computer program, PKULife – **Mindy Fouse**, PKU

Expansion at the Clinic For

Special Children

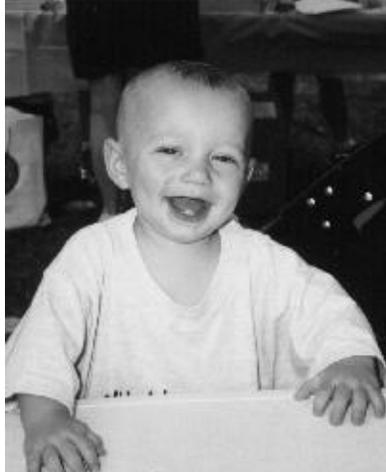
On Saturday, July 28, 2001 The Clinic For Special Children in Strasburg, PA held an open house to unveil their new addition and introduce their new physician. The new post and beam addition, built mainly by volunteers from the Plain community has more examining rooms and offices. The clinic cares for children with over 80 different disorders and has been the recipient of MACPAD research funds. Caroline Morton, Executive Director states that the clinic is now ready to do more in terms of their capability for research.

Dr. Kevin Strauss, from Children's Hospital of Boston, has joined the staff in a full time position. He states he is eager to contribute to the clinic's growth.

The clinic is now looking forward to the annual auction, which generates funds to support their work. This year the auction will be Saturday, September 15, beginning at 8:30am. It will be held at the Leola Produce Auction on Brethern Church Road, north of Route 23 in Leola PA. Handmade quilts and furniture, lawn furniture, soft pretzels and chicken barbeque are just some of the features of the auction. So, make plans to attend the auction and support the clinic's work!

From the minds of children:

Darla, age 3 said about her sister, Donnita, who is 6 and has PKU: "Donnita has PKYou and I have Pkme".



Bobby Griffith

Everyone had fun at the 14TH ANNUAL PKU PICNIC

Great weather, great fun and great smiles! All of these were in abundant supply at our 14th Annual Picnic, held August 4 at the farm of Mr. And Mrs. Harvey Weaver.

We had over 140 people including 39 PKU children/ adults and their families. There was food (PLENTRY of food), games, pony rides, hayrides on the wagon, and baby farm animals for everyone to enjoy.

We started with a welcome from our MACPAD Vice-President, Ken Barton Sr. and son, Kenny **pictured below**.



He in turn introduced our Board President, Judy Griffith who also

welcomed everyone. Sharon and Bob Johnstone did a marvelous job manning the registration table, distributing nametags and literature, selling T-Shirts, cookbooks and PKU Life computer programs. Lynn Trump and Carol Barton, co-chairs for the picnic, organized and served the buffet.

The Lo-Pro buffet was the highlight of the day, with so many different items to taste. Everything from potato salad to pizelles was great. The buffet was scrumptious with every family supplying something good. We want to especially extend our thanks to Mrs. Anna Weaver, who always contributes many different items for the buffet, along with items that she bakes and makes to sell.

Each PKU family received a "goodie" bag with items donated by suppliers.

We had pony rides, a Fish Pond (special thanks to Kara, Mindy and Alyssa for all their help to run that event), PKU Bingo (called by Kenny Barton Jr.....move over Pat Sajak!), the hay rides, and a piñata, generously donated by Smith's Candies in Myerstown, by way of Lynn Trump. In fact, Smith's donated 100 LBS of candy and we are very thankful for their kind gesture. We were scheduled to have a light aircraft fly-over and drop candy for a candy scramble; however, the aircraft had some mechanical troubles and then around 4PM, as the picnic was winding down, we ended up with the weather not cooperating.

We also had our Annual Quilt Raffle. This year we had three additional prizes. Fourth prize was a copy of PKULife, the computer program, third prize was a basket of Lo-Protein food items donated by the Dietary Specialties Shoppe in Philadelphia. Second prize was a lovely wall hanging, made and

donated by Lynn Trump and First prize was, of course, our beautiful quilt made by Mrs. Weaver and her friends.

All-in-all, it was a fun day and a good time for everyone. Again, we extend our THANK YOU to Harvey and Anna Weaver for so graciously allowing us to visit their home.

We are already starting to plan next year's Conference/Picnic so mark your calendars for the first Friday and Saturday in August 2002! See you then!

Carol Barton
Picnic Co-Chair



Enjoying the hayride



Hitting the piñata

Happy Birthday To Our MACPAD Members!!



Steven Droogan-Sept 4
Bailey Clifford-Sept 6
Kimberly Hughes-Sept 13
Alice Wells-Sept 13
Jessica Martinez-Sept 20
Taylor Ann Chandler-Sept 24
Mark Boiko-Sept 25
Jack Robertson-Sept 28
Matthew Jerrehian-Oct 4
Katrina Ruia-Oct 17
Mic Sheard-Oct 29
Robert Griffith-Nov 2
Mary Kate Zimmerman-Nov 2
Gage Fowler-Nov 3
Kyle Gilliano-Nov 10
Sadie Mae Fisher-Nov 18
Johnny Supsic-Nov 29
Beth Matous-Nov 25

Strawberry Banana Freezie

1 cup orange juice
2 tsp honey
½ medium banana
½ cup halved strawberries

Blend in electric blender. Add ice cubes while blender runs at high speed until mixture reaches desired consistency. Approx 25 phe per serving, depending on size of banana.
2 servings per recipe.

Update for PKU Cruise - July 18, 2002

My name is Pat Byrne and I am the travel agent and mother to Krista 13 CPKU who is organizing the PKU Cruise. I want to thank everyone for the wonderful response to our first PKU Cruise. There are currently 18 families traveling on the cruise with families coming from as far as Arizona to join us. It has been wonderful talking to these families from all over the country and sharing ideas and information. There are PKU children, teens and adults from 2 to 27 joining us. The teens have been especially enthusiastic about the cruise. It seems that they feel the same as my daughter in respect to wanting to meet other teens without it being all about PKU with seminars, cooking lessons, etc. They just want to hang out and meet some new friends whom they can talk to.

There is still some space available at the original group rates which start at \$594 per adult, 1st and 2nd passenger in the cabin; and \$344 for children or the 3rd and/or 4th passenger in each cabin. If you are interested and would like additional information you can contact me at Cruise Holidays (610) 277-6850 or by e-mail at wecruise@bellatlantic.net. This space is extremely limited and is available on an availability basis and after the initial quantity is depleted the prices are not guaranteed at the current low rates.

I hope you will join us!

Remember we are a United Way Designated agency in Southeast PA, Lancaster and Blair County.

What Do I Do If My Child Is Sick?

by Karen Blackbird, R.D., M.P.A.

PKU Nutritionist, The Milton S. Hershey Medical Center

Having a child with PKU can cause you to be anxious about other facets of his or her development, can't it? You may watch even more diligently for every developmental milestone: Did he roll over yet? Is he sitting up? He's walking later than my other children . . . is that because of his PKU? What if he has an ear infection or has to go to the hospital? Then what shall I do?

If you are doing your part with maintaining your child's diet and formula intake and keeping his blood phe levels in the target range established by your PKU Treatment Center, you can relax and enjoy his infancy and childhood as you would that of any of your children. You can think of illnesses as little bumps in the road that may affect his blood phe levels here and there, but not cause harm over the long journey. All children have illnesses and children with PKU are no exception. It is important to know, however, that some illnesses will affect your child's blood phe levels and there are some things you should know:

1. If your child has a fever, his phe level may rise. The fever can increase your child's needs for energy. At the same time, a feverish child often doesn't want to eat or take his formula as well. Those two factors combined can cause the child's body to break down muscle stores of protein and use parts of it for energy. When this happens, amino acids (including phe) are released into the blood, making the blood phe level rise.

There are instances during illness where a child's intake of phe is so low that the breakdown of muscle stores still doesn't provide enough phe for his needs. In these situations, the blood phe level will drop. This will usually correct itself as the child resumes eating normally, but he may need some extra phe for a few days to bring the level back into the target range again.

2. You can help prevent the rise in phe caused by a fever. When your child has a fever, encourage him to drink as much as possible and offer drinks that contain calories [sugared drinks, juices, children's fluid replacement drinks, such as Pedialyte, Enfalyte, and your child's PKU medical food (formula)]. Ice pops, regular gelatin desserts (e.g., Jello) and broth are also good choices during illness.

3. If your child is also vomiting, you may need to avoid the medical food for a day or so. Call your PKU Nutritionist in these instances for advice specific to your child. If your child is unable to keep down any fluids at all, contact your physician. Depending on the age of the child, an episode of vomiting after taking the medical food can leave an association in the child's mind that is hard to overcome later (i.e., that the medical food *causes* vomiting). For this reason, even if your child tolerates small amounts of fluids, you may need to stay away from the PKU medical food for a day or so, while offering the calorie-containing liquids mentioned above instead. This will not harm your child. When you are ready to resume the medical food, make it more dilute for the first day (half the amount of powder mixed with the usual amount of water) to be sure your child tolerates it. Also, if your child has been vomiting, any fluids you give to him are usually better tolerated in small amounts, given more frequently (start with only 1-2 Tablespoons; if he tolerates this amount, give another few Tablespoons after about 15 minutes, etc.).

4. If your child has diarrhea, avoid fruit juices. Fruit juices often make diarrhea worse. Use other clear fluids mentioned above, especially those that contain sodium and potassium (broth, Pedialyte, Enfalyte, Pedialyte Pops). Keep in mind that many antibiotics cause diarrhea. If your primary care pediatrician recommends giving yogurt to your child to increase the bacteria in his digestive tract, check with your PKU nutritionist first. There are alternative products which do not contain phe.

5. Notify your pharmacy that your child has PKU before filling your first prescription. In fact, I recommend that parents tell the pharmacist to enter "phenylalanine" as an *allergy* in their computerized database. Even though PKU isn't an allergy, this is the most effective way to "red flag" a medicine as containing phe before the prescription is filled. Most medicines do not contain huge amounts of phe, but you want to know how much so you can adjust the diet if necessary. Don't panic if you have unknowingly given your child a medicine containing phe. There are very few medicines that contain enough phe to significantly alter a child's phe level.

6. Read labels on over-the-counter medicines looking for this alert: “Attention Phenylketonurics: Contains Phenylalanine”. There are usually phe-free alternatives for over-the-counter medicines. Virginia Schuett has a list of the phe content of various drugs on her website: www.pkunews.org.

7. Follow your primary care physicians instructions for illness. Except for the diet-related advice above, illness and injury in a child with pku is treated the same as for any other child.

8. If your child is hospitalized, contact your PKU treatment center. It is important for your treatment center to know if you child is admitted to a hospital, for whatever reason. Your PKU physician and nutritionist will want to be a resource for any feeding-related questions that arise during your child’s hospitalization, especially if your child requires intravenous (by vein) feedings.

9. Finally, don’t be afraid to ask questions of your physician and nutritionist. Being well informed usually helps to reduce unnecessary anxiety, so keep those questions coming!

Thanks To Our Suppliers For Their Sponsorship of the 14th Annual Picnic



Thanks to Emily Baker and SHS International for their generous donation of product samples which were distributed at the picnic! Each PKU/MCAD person left with a bag full of SHS foods or drink mix.



Thanks also to Chelsea Smith at The Dietary Specialties Shoppe for the donation of a lovely basket full of their products. Be sure to read the article in this newsletter about their new product additions.



Thanks to Intersoft Designs for donating our fourth prize at the raffle which was a copy of PKULife, the computer program designed to monitor the PKU diet. They also donated a part of the proceeds for each copy that was sold at the picnic.



Thanks to Sandy for sending the variety of samples which were distributed at the picnic!

ATTENTION ALL PKU/MCAD PEOPLE WHO ATTENDED THE ANNUAL PICNIC ON AUGUST 4 !



Due to a carrier error, the products that Ener-G Foods had planned to distribute at our picnic, did not arrive on time. **Sam Wylde III of Ener-G Foods has graciously agreed to ship these products to MACPAD, who will distribute them to those individuals who were at the picnic!** Mr. Wylde has even agreed to reimburse MACPAD for the postage! So, watch for a package from MACPAD/Ener-G! Mr. Wylde says it will take several weeks because he would like to include a package of his new Low-Protein Baking Mix, along with several other products. Thank You to Ener-G Foods!

New Product Additions at The Dietary Specialties Shoppe, Inc.

Thanks to all the support and promotion of our shop we have been able to satisfy requests for new low protein/low phe items. Our expanded product selection includes the following new items:

Aproten Rusks, a cracker toast for spreads, snacks or making bread crumbs. These small squares have been received well by the young as well as the old. (Very light 100gm = <50mg phe)

Loprofin Sweet Biscuits, simple and slightly sweet these cookies make a perfect compliment with tea or dipped in low protein chocolate. (2 pc =2.2mg phe)

Ener-G Low Protein Pastas are back!! We are stocking the macaroni, spaghetti and shells shapes. (2oz dry = 5mg phe)

ChiChi, looks like rice but is really a pasta that is also a source of calcium. Use in soups, cold salads or as a side dish. Please keep your suggestions and feedback coming so we can continue to grow and better serve your needs.

For a complete product listing please call 215-242-5302 or e-mail us your address to dietaryshoppe@juno.com. Orders can also be processed on our website. <http://dietaryshoppe.com>



Wanted: PKU Hand Prints

Lynn Trump, creator of the wall hanging door prize at this year's picnic, has a unique idea for next year's picnic! Lynn plans to create a quilt with a handprint from each individual with PKU or Allied Disorder; however, she only has 31 handprints and would like to have others. If you or a family member was at the picnic and did not have their handprint traced, please trace the handprint, include date of birth and name, and mail to Lynn Trump, 921 Hilltop Road, Myerstown, PA 17067 or to MACPAD. The quilt winner will be chosen from those individuals who are present and also depicted on the quilt. There will be no ticket sales, just a drawing for the quilt! Send those handprints!

Random Reflections

The summer has been full of activity for our family and I am sure for yours. Our son Joe had his 21st birthday this month. He is gearing up for the start of his junior year at Furman University. We are making plans for what will be needed to equip his on campus apartment kitchen! This is very different than the plans we made for his first week at pre-school or the start-up for elementary school.

As I reflect on helpful tools for our son's entry into the public school system here in Central Pennsylvania, we secured a publication from the US Department of Health and Human Services entitled "PKU and The Schools"- Publication No. (HAS) 80-5233. We asked that it be placed in his file so that teachers and other school personnel would have easy access to information about PKU. Several clinics offered "Teacher's Guides to PKU" and we included those as well.

We also asked the secretary of the school food service to mail us the menu each month. We were better able to plan "packing lunch" or "buying". In the elementary years a small thermos cooler was chilled with ice each night so that "his milk" was cold. Our son was made aware to avoid anything with Nutrasweet and the teaching staff was alerted to it as well by us. Being creative with what to "pack" was a challenge but one that we worked through even this summer when he was working for a construction contractor! Interesting to note, that those men were as curious as to what he would be eating as the children in grade school!

A nugget of wisdom—Release children full force into the world of education, excited about the

adventure, loving themselves, loving what is different about themselves, and embracing what's different about other people!

Cindy Hoover
PKU Mom



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.

Everyone says the formulas really don't taste that well. Should my daughter be using flavorings to improve the taste of my granddaughters drink?

Some individuals do add flavoring such as the Bickford flavor extracts to formula drinks. Others feel that if the child likes the taste of the formula, we should not interfere and allow the child to have the formula the way they get used to it.

You can suggest this for her but
Diet for Michael's Life

allow your daughter and your granddaughter to make the final decision.

Now that I have a grandchild with PKU, should I purchase low protein foods to have in my home or should I expect my son's family to provide these foods?

Low protein foods are more expensive than other foods. Does your son purchase cases of food for their child? Do they live close enough to you that you will need them on a regular basis? Will you be babysitting the child on a regular basis? All of these questions would factor into the decision.

If they purchase foods by the case and you will have the child on a regular basis, they should provide you with enough products to make the child comfortable in your home. Also this will avoid having the mom carry every meal to your home. By having some "special" foods at your home it may assist the child in learning about diet.

If you feel that you can afford the food, then discuss with your son what you plan to purchase and when you will be able to prepare it. Be sure to discuss daily phe intake with the parents before you prepare foods for the child.

T-Shirt Sale

MACPAD T-shirts are now on sale for \$6.00 each. All sizes are not available. Contact MACPAD for details of sizes or send your check for \$6.36 and size requested. We will contact you if your size is not in stock.

A severe weight gain accompanied by increased irritability and an almost lethargic state ultimately brought Michael, at age 33, back to the PKU program at Newark Beth Israel Medical Center. As preparation for our first appointment in November 1999, Dr. Haratounian ordered a phenylalanine level determination by the lab. In the meantime, Ms. Sara Wiley provided us with the directions to the clinic and a “Don’t Worry” telephone directory of names, numbers and hours available. Despite the strong support we immediately felt from the staff, we approached our initial meeting with some apprehension, remembering a consultation several years earlier with a well-meaning doctor in Philadelphia who had advised us not to return to the PKU diet on the grounds that it would be far too difficult for Michael and might not produce the intended results.

Our first meeting entailed a series of extensive interviews and evaluations, during which we learned of Michael's off-the-scale phenylalanine level. These evaluations culminated in Dr. Haratounian strongly advising Michael to resume the PKU diet. After the rather grim picture painted by our consultation years earlier, we were extremely grateful and energized by Dr. Haratounian's conviction that while a return to the diet would be difficult, it would be both doable and necessary. We left the hospital that day with a variety of formulas for Michael to try, a packet of info to digest and a very good feeling about the people with whom we would be working—a feeling that would intensify over time.

Everyone wanted Michael to make a successful transition. Because he really enjoyed eating, we focused our efforts on making the diet as appealing as possible. The doctor suggested that Michael follow a modified version consisting of certain fruits and vegetables allowed in unlimited quantity and others that were to be consumed in specified portion sizes. We used these lists and the Low Protein Food list (compiled by Virginia Schuett, MS, RD.) to check the phe-levels of his favorite fruits and vegetables as well as processed foods. Michael and his wife Isabel refer to these lists in the planning and preparation of meals. We also reviewed Low Protein Cookery by the same author, and marked certain recipes for ready reference. We had two main criteria when choosing a recipe: (1) It sounded good to Michael (2) It was relatively easy to prepare. At the same time, we tried to provide as much variety as possible.

The most critical element of a successful transition, however, was to find a formula he liked well enough to enable him to consume the required three to four servings everyday. This turned out to be easier than expected—the options had expanded remarkably from the sole Lo-Phenylac that had existed 26 years earlier. Michael drinks Maxamum as his primary formula and eats one Flexi-10 bar per day. Among other things, the Flexi-10 bar eliminated the need to carry a large volume of formula to work.

Because Michael and Isabel both work Monday through Friday, Saturday mornings were earmarked as recipe testing and bread baking days. Both the bread machine and the digital balance helped to ensure accurate measurements critical to the bread making. We used the baking times to try new recipes. We experimented with different seasonings and spices and introduced low protein rice, pastas and snacks, all in an effort to develop menus that satisfied Michael's tastes and minimized any sense of deprivation. Homemade peanut butter was an instant winner.

While baking is a less expensive alternative to purchasing prepared breads, Michael really likes the frozen bagels and rolls, and finds them convenient for packing lunches. Low Pro pasta, vegetable and fruit salads also work well for meals on the go. Those of you familiar with the diet are probably aware of the expense of commercially prepared low protein substitutes for those foods that are an integral part of a typical adult diet. This expense was one that Michael and Isabel's salaries could not support. Because we were convinced of the important role these foods played in making the diet more appealing, his father and I assumed the responsibility for them. We've recently learned, however, that New Jersey is one of several states who require health insurance to cover the purchase of medically prescribed low protein foods. Without the assistance of this insurance, most young adults would probably find the cost prohibitive.

Michael and Isabel find routine with respect to formula making and menu planning facilitate adherence to the diet. They plan their menus a week in advance, always making sure to have a supply of fresh fruits and vegetables and low protein treats on hand, and Michael finds it helpful to prepare his formula for the next day in the evening. Preparation of this sort helps to reduce impediments to following this demanding but rewarding diet.

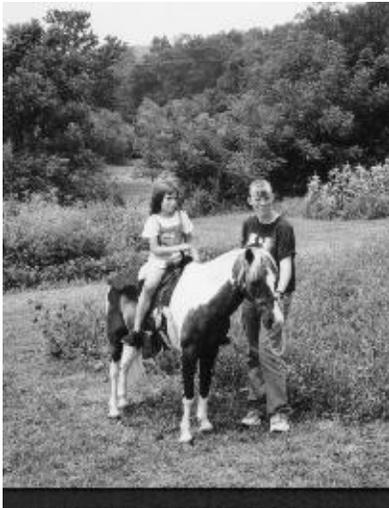
When dining away from home, either in a restaurant or a friend's home, Michael has learned that anticipation helps. A quick phone call before going to a new restaurant can ensure that their menu can accommodate his needs. When ordering, he specifies which fruits and vegetables he'd like, having learned the expensive way that a “vegetarian platter”

frequently includes more than vegetables, and may include all kinds of high protein food. He also takes his own bread with him. Bringing a low protein snack and an entrée that can be popped into the microwave to a friend's home can save embarrassment if the menu is not appropriate and can be done very inconspicuously.

Almost two years have passed since Michael returned to the diet. For the most part, Michael finds it quite manageable—more so than we anticipated. The frequent monitoring of phenylalanine levels keeps him on course by sending him signals about the ways his eating might need to be adjusted. But without a doubt, the greatest incentive for Michael was an almost immediate improvement in how he felt about himself. Adhering to the diet and working out regularly, Michael has lost about 100 pounds and enjoys an active life style and a happy, even temperament. He is keenly aware of the changes attributable to the diet and is grateful to the entire staff of the PKU program at Newark Beth Israel and to his loving wife Isabel for their continuing support. Our entire family is thankful for the professional expertise that the staff affords Michael as he continues his commitment to this challenging but rewarding diet.

Jean McConnell
PKU Mom

More Pictures of the 14th Annual PKU Picnic



Having fun on a pony ride



Carol Barton and the fish pond



Kim Pepper and son, Noah



The Ruias' playing PKU Bingo



Making friends



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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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