

The Third Annual National PKU Awareness Month- 2008!!!

It's hard to believe that we are approaching the third annual National PKU Awareness Month! In the past 2 years we have raised over \$500,000 for PKU research, through lots of hard work by PKU organizations across the country! This year there are 23 scheduled events and 9 more in the planning stages! Scattered throughout this newsletter are notices about these events- check to see if one is in your area and plan to attend. If there isn't one in your area, why don't you plan one? Contact info@MACPAD.org

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A letter from the President – February 2008



This year MACPAD will celebrate its 10th Anniversary! We will have an Anniversary Conference in August at which we will discuss many of the PKU treatments to which we have contributed by raising money for research and by sponsoring and assisting in National PKU Awareness month, which is held in May every year.

This year we hope to reach another milestone for PKU. Three members of the MACPAD board, including me, Bob Johnstone (our Treasurer) and Sharon Johnstone (our PKU Awareness Month coordinator and Newsletter Editor), have been working with a group of other PKU support group leaders throughout the country to develop a national PKU organization. This organization, which will be called **National PKU Alliance (or NPKUA)**, will be a giant step for the future of PKU.

The **National PKU Alliance** will be formed in the next few months upon the solid foundation of the PKU organizations that have existed for the last 20 years. These member organizations, including MACPAD, will direct the national organization to accomplish goals that one local organization alone could never achieve.

The NPKUA will work to support the local PKU organizations, will work directly with individuals to help them form their own local support groups, and will form a medical advisory board to help us evaluate research proposals and direct the thousands of dollars that our members raise every year. The NPKUA also will work toward affecting our lives in bigger ways, including working on insurance coverage issues, uniformity of treatment, and availability of food and formulas. With the support of this new organization, MACPAD will become stronger and even more successful in accomplishing its mission to enrich the lives of those living with PKU.

In addition to its work with PKU, the NPKUA will work with national and local organizations supporting other metabolic disorders in addressing common issues and in working toward common goals. With these bonds, we hope to unite the entire metabolic community to have an even greater impact.

If you are interested in participating in these exciting developments with MACPAD, please contact me or a member of our board to find out what you can do to help.

Judy Griffith, President and Mother of 4 kids (2 with PKU)



WALK FOR PKU RESEARCH SPONSORED BY THE MID-ATLANTIC CONNECTION FOR PKU AND ALLIED DISORDERS, INC.
* a portion of the proceeds will be donated to Ohio PKU Camp

3rd Annual State of Ohio

PKU Walk-a-thon

When: Saturday, May 31st, 2008
Where: Miami Whitewater Forest
Harrison Pike, Off I-74, Dry Fork Exit
\$2.00 Park Admittance Fee

Schedule:

- 9:00 am to 10:00 am Check in & turn in donations, a T-shirt will be given to any walker that is present with a donation of at least \$25.00, one shirt per walker please
- 10:00 am to 10:15 am Speaker, Raymond C. Stevens, Ph.D.
Stevens Lab from The Scripps Research Institute in LaJolla, CA
- 10:15 am to 11:00 am Walk for Awareness & Research
11:00 am to ? Social Gathering, feel free to bring your favorite PKU recipes to sample, low protein snacks and water will be provided

A prize will be given to the family who brings the most pop tabs, that our group will be donating to Cincinnati's Ronald McDonald House.

More details to Follow. Brings chairs and umbrella's if needed.

The park has two easy paved trails. One trail is 1.20 miles & the other is 7.80 miles. Feel free to bring your bikes or roller blades!

If you have any questions or need directions, please contact Shelly Cribbet @

(513) 266-5322 or by e-mail, cribbets@hotmail.com

More information about the Walk can be found on the MACPAD website, www.macpad.org



