

# PKU Georgia News

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## Welcome to PKU Georgia!

PKU Georgia is a group of Georgia residents who have come together with PKU as a common interest. We communicate primarily online through Yahoo Health Groups. Our goal is to arrange social, educational, and fundraising events. Our first fundraiser, the PKU Ga Ultimate Frisbee Tournament was held this May and was

a great success! We are all looking forward to a fall banquet planned by members Timmy and Jennifer Lee.

We are very excited to present our first newsletter and hope you will find some useful information inside! Our focus for this newsletter is to introduce our group, share informa-

tion about some regional resources available to Georgia residents, & discuss some recent news items relevant to PKU. We've included a favorite PKU recipe as well.

In the future, we'd love to have PKU Georgia members contribute columns, recipes, and photos for newsletters.

To join PKU Georgia, visit

<http://health.groups.yahoo.com/group/PKU-Georgia/>

## GINA

This past April, the United States Senate unanimously passed the Genetic Information Nondiscrimination act (GINA). Congress passed the bill 441-0 on May 1. The National Human Genome Research Institute states that

"GINA will protect individuals against discrimination based on their genetic information when it comes to health insurance and employment. These protections are intended to encourage Americans to take advantage of genetic

testing as part of their medical care."

The bill will now go to President Bush for signing.

Find more information at [www.genome.gov](http://www.genome.gov).



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## Newborn Screening Saves Lives Act

(From HealthNewsDigest.com.)

Senators Chris Dodd (D-CT) and Orrin Hatch (R-UT) recently reintroduced the Newborn Screening Saves Lives Act. (Hooray for non-partisan politics!)

According to the March of Dimes, this Act will provide \$15 million in funding

"Screening for treatable conditions immediately after birth can mean the difference between a healthy life or a severe disability or even death for a newborn."

for educating parents and health care providers about newborn screening .

Funding will also improve follow up care for infants with illnesses detected through newborn screening. For more information, visit the March of Dimes website at

<http://marchofdimes.com>.

## What is SERGG?

From the SERGG Home Page:

The Southeastern Regional Genetics Group, Inc. is a network of providers of clinical genetic services, public health departments, consumers, and related laboratory services, working together with affected individuals and their families.

Mission Statement:

- Enhance and promote the quality of genetic services in the Southeastern Region which includes the states of Alabama, Florida, Georgia, Louisiana, Mississippi, North Carolina, South

Carolina, Tennessee, Puerto Rico, and the Virgin Islands.

- Provide a forum for exchange of information among professionals who provide genetic services and the consumers of these services in the southeastern region of the United States.
- Receive and administer funds for coordinating genetic services and for furthering education about the delivery of genetic services.
- Interact with other regional and national genetic organizations.

- Arrange and promote proficiency testing and quality control in genetic services.

The SERGG website includes a great feature called "Ask the Geneticist."

Questions that meet criteria are answered and posted to the website. Find this resource at <http://www.askthegen.org/>.

More information about the Southeastern Regional Genetics Group, Inc. can be found at [www.sergginc.org](http://www.sergginc.org).

## USMD-PKU

Unified to Support Metabolic Disorders (USMD-PKU) is a 501c3 nonprofit corporation that focuses on improving the lives of individuals with PKU through advocacy, education, support, awareness, and collaboration with the IEM support organizations across the country.

USMD is an ALL VOLUNTEER organization which means donations go directly to help those affected by the disorder. USMD supports grassroots efforts across the country.

For more information, visit <http://www.usmd-pku.org>.

## Emory Genetics

The Emory Metabolic Nutritional Program, administered by Rani H. Singh, Ph.D. R.D., offers complete services to manage metabolic disorders including: Inpatient and Outpatient Nutrition Management; Diet and Formula Instruction; Computer Diet Analysis; Medical Foods Distribution; Cooking Classes; Group Classes; Research; and a Metabolic Food Store!

In addition, the Emory Division of Medical Genetics conducts a one-week summer camp on the campus of Emory University for young women, ages 12 and up, who have phenylketonuria (PKU) or maple syrup urine disease (MSUD). Young women attending the camp are involved in a range of activities for education and support. The camp concludes each year with a banquet for campers, their parents, the genetics faculty, & other healthcare professionals. For more information or to learn how you can support the camp contact Rosalynn Borlaza (Camp Coordinator) at (404) 778-8521.

Members of PKU Georgia would like to thank Dr. Singh and her staff for supporting our first PKU Awareness Event! We would also like to thank USMD-PKU, Cambrooke Foods, Vitaflo, Biomarin, Nutricia, & Ener-G foods for their support!

## Recipe of the Month

### Cheesy Rice

- 1/4 cup (cooked) Uncle Ben's original white rice *45 mg phe*
- 45 g (dry) Dietary Specialties imitation rice *5 mg phe*
- 20 g Cambrooke cheddar shreds *30 mg phe*

- 1/2 tbsp margarine
- 18 g green peas *36 mg phe*
- Salt & pepper

Cook rice according to package directions. Coat rice with margarine and sprinkle with salt. Add cheddar shreds and mix well. Add peas last.

Total phe for recipe:

116 mg of phe/ 7 1/2 exchanges

Lower Phe Variations:

- Reduce the amount of Uncle Ben's rice & increase the DS rice
- Use diced green beans instead of peas (20 g canned or frozen green beans=10 mg phe)