



Summer 2009 NEWSLETTER

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Mark Your Calendar

September 2009

Kuvan Sponsored
Town Hall Event
Chattanooga Aquarium

October 2009

Food for Thought Dinner
and Silent Auction

Ultimate PKU Day 2009

Our first official Georgia PKU Connect event was held in May 2009. Events included an Ultimate Frisbee Tournament and children's carnival. Scott Vanags organized a great contest for about 60 Ultimate players, with prizes going to the players raising the most money for PKU awareness.

The kids had a great morning jumping in the inflatables, playing games for prizes, and getting their faces painted. We all enjoyed goodies from Cambrooke, Applied Nutrition, Ener-G Foods, and Dylan's Candy Bar. A special thanks to our many sponsors, volunteers, and participants!

We hope to see you all again next year!



PKU Advocacy

The National PKU Alliance and Georgia PKU Connect need your help to advocate for improved coverage of medical foods (formulas), modified low-protein foods and nutraceuticals!

In the last 3-4 years state budgetary cuts have reduced assistance for PKU treatments through state programs and magnified the difficulty of finding PKU friendly insurance. Georgia does not have legislation mandating coverage of PKU medical formula and foods. In addition, coverage for PKU

is inconsistent across the United States making it difficult, if not impossible to ensure access to

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Did You Know..?

Georgia is one of only 12 states without insurance mandates!
What can we do about it? Call our state legislators!
Visit <http://www.legis.state.ga.us/> for contact information.
Tell them how PKU treatment expenses affect you!

Recipe of the Season

Grilled Vegetable Salad

Thanks to Jennifer Lee for sharing the following recipe, featured at this year's Network PKU Conference.

From: "Cold Soups and Summer Delights," Chef Birch DeVault, MED

Ingredients: Preparation:

5 oz (140g) onions, sliced 1/2 inch thick
4 oz (112g) zucchini, sliced on the bias 1/2 inch
4 oz (112g) red or yellow peppers sliced 1 inch
4 oz (112g) green peppers sliced 1 inch thick
1/2 tsp salt
4 TBS cider vinegar, divided
2 tsp orange juice concentrate
1 TBS parsley, chopped
1 TBS tarragon, minced
4 TBS olive oil, divided

Preheat grill to medium high. In large bowl, toss vegetables together. Season vegetables with 1/4 tsp salt, 2 TBS olive oil, and 2 TBS vinegar. Toss gently to coat. Place vegetables in barbecue grilling basket or directly on grill. A griddle preheated to high will also work. Grill vegetables for 10 to 12 minutes per side until lightly charred and tender. Remove vegetables from grill and place in large bowl. Whisk remaining salt and vinegar with orange juice concentrate and herbs. Slowly drizzle in remaining olive oil. Toss and serve.

Yield: 6 servings :: Serving size: 3 oz. :: Protein: 1.05 g :: Phe: 33.1 mg per serving



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PKU Advocacy

healthcare and required treatments for PKU when moving from state to state or between jobs.

The NPKUA is requesting that families and individuals visit www.NPKUA.org to learn how to submit a personal healthcare story! Your words explaining the challenges and costs of living with PKU will be used at a federal level to support legislation specifically written to improve PKU coverage.

Personal healthcare stories are also needed to advocate in Georgia. Please forward your submission to advocacy@georgiapku.org to help!



Join Today! Membership is free.
Visit www.georgiapku.org
for more info.

About Georgia PKU Connect

Our Mission

Georgia PKU Connect, Inc. is a 501c3 nonprofit dedicated to improving the lives of Georgia's Phenylketonuria (PKU) community. Our mission is to support individuals and families through camaraderie, education, advocacy and research.

Guiding Principles

- Strengthen and support the Georgia PKU community by reaching out to as many individuals, families and organizations as possible
- Serve individuals with PKU regardless of age or level of treatment
- Collaborate with medical professionals and nonprofit organizations sharing our mission
- Raise funds for educational initiatives, research programs, and community building activities
- Advocate for affecting persons and families for coverage of required treatments
- Increase public awareness of PKU and other inherited metabolic disorders
- Participate in the development of educational materials and assist in their distribution
- Support the newborn screening recommendation of the American College of Medical Genetics (ACMG)

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