



Organizational Summary

History

Georgia PKU Connect was founded in 2008 by three mothers, each with a child born with Phenylketonuria (PKU). Support for the organization was cultivated through an online, Georgia focused PKU Yahoo Group and the inspirational spirit of Emory University's Metabolic Nutrition Team. The successful launch of Georgia PKU Connect can also be attributed to the positive energy and contributions of local families and adults with PKU.

What is PKU?

Phenylketonuria (PKU) is an inherited metabolic disorder. Individuals with PKU cannot process a part of protein called phenylalanine (phe), which is present in most foods. Affected individuals lack or have very low levels of an enzyme (phenylalanine hydroxylase or PAH) that converts phe to other substances the body needs. Without treatment, phe builds up in the bloodstream and causes severe neurological complications, including mental retardation. The standard treatment consists of a strict diet very low in phenylalanine and daily consumption of special formula containing life sustaining nutrition. If the diet is adhered to, individuals with PKU can grow up normally. Continued research is needed to ease the difficulty of the diet and improve the quality of life for all individuals living with PKU!

Mission

Georgia PKU Connect, Inc. is a 501c3 nonprofit (STATUS PENDING APPROVAL) 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)

Organization Features

Online Support Group – “PKU Georgia”

PKU Georgia is a discussion forum, information storage area and calendar of activities for residents of the state of Georgia with Phenylketonuria (PKU), as well as their families and medical support professionals. Some current functionality will be transitioned to GeorgiaPKUConnect.com.

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

Newsletter – “Georgia PKU News”

- Issue 1 – May 2008
- Issue 2 – December 2008

Website – www.GeorgiaPKU.org

- Home Page (Page Links, Our Mission, Corporate Sponsor Logos and Links, Donation Link)
- About Us (History, Mission & Guiding Principles, Board of Directors, Organization Contact Information, By-Laws)
- Personal Stories
- News & Events (Georgia PKU News - 2 editions, News Flashes, Event Information)
- Resources (Websites of Interest, Medical Food and Low Protein Food Companies, Literature Listing, Recipes, Cookbooks/Diet Reference Information)
- Get Involved (Become a Member, Volunteer Opportunities, Become a Corporate Sponsor, Donation Information & Link, Contact Us)

Fundraising, Awareness and Educational Events

- Taste Connection Cooking Workshop with Malathy – February 7, 2009
- Ultimate PKU Day – Ultimate Frisbee Tournament and Children's Carnival – May 16, 2009
- Food For Thought Banquet – Fall 2009
- Other (TBD)

