



georgiapku.org



## About Us

### Our 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 discussion 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 (commonly known as PKU) is a rare genetic disorder affecting protein metabolism. Individuals with PKU cannot process the amino acid phenylalanine, which is present in most foods. Without treatment, phenylalanine builds up in the bloodstream and causes severe neurological complications, including mental retardation. To prevent damage, a strict diet very low in phenylalanine and daily consumption of special formula containing life sustaining nutrition must be started shortly after birth. Managing PKU is difficult and presents social and economic challenges. If the diet is rigorously adhered to, individuals with PKU will develop normally. Continued research is needed to improve treatment options and pursue a cure.

### Our Mission

To connect PKU families and individuals with the support and resources they need to manage PKU and live healthy, productive lives.

### Board of Directors

Kristen Vanags, President (Officer), Board Chair

Shiela Ryan, Vice President (Officer)

Steve Hunt, Treasurer (Officer)

Julie Cheek, Secretary (Officer)

Scott Vanags, Parent Representative

Anna Parker, PKU Adult

Fred Jewell, Business Representative

## Committees

### Outreach/Support

Outreach and Support creates opportunities to connect PKU community members with the organization, and members to members. This committee also provides educational resources and community activities to promote a holistic supportive environment.

*Examples of outreach and support include new patient welcome packets, facilitation of message boards/email loops, development and distribution of newsletters, community building social activities, and educational workshops.*

### Advocacy

Although the law requires every state to screen newborns for PKU, there is not adequate coverage for the required treatment. The advocacy committee raises awareness for this issue and promotes solutions to ensure affected children and adults have access to the medical foods required to treat the disorder. Treating PKU throughout the lifespan allows children to become healthy and productive citizens.

*Examples of advocacy include development and support of state and federal legislation providing equitable insurance coverage of medical foods and educating caregivers about the use of 504 plans in public schools.*

### Support Research

While the primary objective of Georgia PKU Connect is to support the community dealing with the management of PKU, the Research committee will maintain a connection to research for improved treatments and a potential cure. This committee will participate in the National PKU Alliance's Research Committee and keep the Georgia stakeholders up to speed on the developments and opportunities for future research.

### Fundraising

The fundraising committee is primarily focused on identifying, developing and implementing fundraising opportunities. Its members work closely with the executive committee to identify the financial needs of the organization and develop the governance model for allocating funds.

*Examples of fundraising activities include the Annual Ultimate PKU Day, walks/runs for PKU, golf tournaments, lemonade stands, applying for grants, planned giving, and the facilitation of corporate donations.*



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### **Board Development**

This committee is responsible for the design of the board.

*Examples of committee activities include studying the current membership, determining skills and experience needed, recruiting and nominating new members, defining board member roles and responsibilities, and conducting board training exercises.*

### **Volunteer Management**

The volunteer management committee creates a pool of volunteers, identifies volunteer needs (what projects and skills), develops a method of tracking volunteers, and coordinates volunteers.

*Examples of activities requiring volunteers include the Annual Ultimate PKU Day fundraiser, community building events, and educational workshops.*