



### 2011 Board Members

Kristen Vanags (President), Shiela Ryan (Vice President), Steve Hunt (Treasurer), Julie Cheek (Secretary), Scott Vanags, Anna Parker, Fred Jewell

## Greetings

We hope this newsletter finds you well and that your winter season has been wonderful! Georgia PKU Connect has been busy expanding our board (see above) and planning events for the upcoming year. We are excited to implement some of the great ideas that were discussed during our strategic planning meeting held in Atlanta last fall and hope to host more group activities to build relationships among Georgia's PKU families. Read on for more information about what's in store for 2011!

## Advocacy News

**Let's Move for Medical Foods!** The "Federal" Medical Foods Equity Act has been reintroduced in the U.S. Senate and House of Representatives! Let's work together to improve medical formula and food coverage. Please contact your U.S. Congressional Members to ask for their support and co-sponsorship! The Senate Bill number is S.311 and the House Bill number is HR.1311. When you call their offices, ask to speak with the Health Legislative Assistant. Additional information and advocacy guides are available on the NPKUA.org website.

**What about the Georgia bill?** Earlier this year, House Bill 132 was introduced in the Georgia Assembly by Representatives Edward Lindsey 54<sup>th</sup> District, Ben Watson 163<sup>rd</sup> District and Stephanie Benfield 85<sup>th</sup> District. Through the leadership of Christine Cox (President of the Georgia Medical Foods Coalition) and the efforts of our clinicians, the Georgia March of Dimes, and many Georgia PKU community members, we were successful in raising awareness for PKU and the importance of medical formula and low-protein food coverage! The Georgia Medical Foods Equity Act will be re-introduced in the next legislative session and we will need your help to continue building support. Together we can have a strong voice!

Please contact Kristen with any federal or state advocacy questions - she is happy to help you!  
kristen@georgiapku.org or 678-612-8408

*Your personal story will make a difference for Georgians and many others throughout the United States.*

## What's New in 2011?

In anticipation of growing and reaching more families, we have formed several committees to address various needs within the community. If you see an area that appeals to you, please contact the head of that committee. We'd love to have your time and talent to make this year the best yet!

Outreach/Support: Shiela Ryan  
shiela@georgiapku.org  
Support Research: Scott Vanags  
scott@georgiapku.org  
Volunteer Mgmt: Joanne Hunt  
joanne@georgiapku.org  
Fundraising: Shiela Ryan  
shiela@georgiapku.org  
Advocacy: Kristen Vanags  
kristen@georgiapku.org

### PKU Community Picnic!

Saturday, June 4th, 11am - 3pm during Ultimate PKU Day

Bring a picnic lunch and join us under the big tent!

Granite-Pattillo Field, 4670 Granite Drive, Tucker, GA 30084

We can't wait to see you! - RSVP to Kristen

678-612-8408 or kristen@georgiapku.org

## 2011 Events

### Low-Protein Cooking Event

Held in March - Visit [GeorgiaPKU.org](http://GeorgiaPKU.org) for photos!

### PKU Awareness

Throughout the Month of May

### Ultimate PKU Day

Saturday, June 4th

*Ultimate Frisbee Tournament, 8am-5pm*

*Community Picnic, 11am-3pm*

### Walk for PKU

Fall Season, Date Coming Soon!

### Annual Meeting and Holiday Party

Early December

## 2010 Fundraising Update

With your help, Georgia PKU Connect donated \$9,768 to support research and clinical programs for PKU!

Would you like to play Ultimate Frisbee for PKU?

Call Scott or visit the [GeorgiaPKU.org](http://GeorgiaPKU.org) News & Events page for the latest information!

[www.GeorgiaPKU.org/NewsEvents.html](http://www.GeorgiaPKU.org/NewsEvents.html)  
[scott@georgiapku.org](mailto:scott@georgiapku.org)  
404-202-1391

## National PKU Alliance

We'd like to encourage our members to consider joining the National PKU Alliance! The NPKUA works to consolidate the efforts of PKU organizations around the nation so that we can have a collective voice in raising awareness, supporting research, and advocating change for those affected by PKU. Membership is \$25 and comes with great discounts on low protein foods, including a \$100 gift certificate for Cambrooke! For more information, visit [www.NPKUA.org](http://www.NPKUA.org).

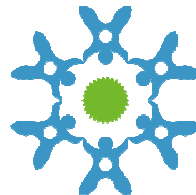
## Are you receiving our emails?

**Georgia PKU Connect frequently sends announcements and updates through email.**

If your contact information has changed (or if you are not receiving emails from us), call Cynthia at 770-813-1145 or email [CynthiaHunt@comcast.net](mailto:CynthiaHunt@comcast.net) with your name and updated information (mailing address, phone, email, and relationship to PKU).

**Thank you for staying connected!**

The Membership Team (Julie and Cynthia)



**GEORGIA PKU**  
**C O N N E C T**

Georgia PKU Connect, Inc. is dedicated to improving the lives of Georgia's Phenylketonuria (PKU) community. Our mission is to connect PKU families and individuals with the support and resources they need to manage PKU and live healthy, productive lives.

## New Low Protein Food List

The third edition printed version of Virginia Schuett's Low Protein Food List contains 288 pages with more than 6,000 food entries. The book is now available, with an online version in the works. Please note that this version does not include baby foods. A list of baby foods with phenylalanine information will be available as a free download on Virginia's website as soon as she is able to verify her data. Visit [www.pkunews.org](http://www.pkunews.org) for more information.

### Note from Virginia for families/adults with PKU:

If you cannot afford the food list, please contact National PKU News ([schuett@pkunews.org](mailto:schuett@pkunews.org)). Describe your financial circumstances and provide your complete address with zip code. You may qualify for a free or discounted printed version of the food list, provided through the generosity of The National PKU Alliance.



Sponsors of Georgia PKU Connect, Inc. include:



[georgiapku.org](http://georgiapku.org)