



## Spring 2010 NEWSLETTER

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### MARK YOUR CALENDAR



## Ultimate PKU Day Sat., June 5, 2010

Our annual Ultimate PKU Day will be June 5 at Granite Field in Tucker, Georgia! This event includes an Ultimate Frisbee tournament, children's activities, and picnic area to socialize with PKU community members. Registration information for ultimate players and general attendees will be available in early April. Stay tuned for more Ultimate PKU Day details!



Field space has been donated by the Tucker Youth Soccer Association. Thank you, TYSA!



## Mrs. Vanags Goes to Washington

*"I believe passing medical foods legislation is possible and I hope you do too!"*

It was the week before Thanksgiving and I was furiously making appointments with members of Congress. In a few short days I would be at the U.S. Capitol. I was scared! I wondered if I would be able to articulate my passion for medical foods coverage, my family's story and the basics of PKU. At my request, my father made a call to his congressman, John Sarbanes of the 3rd District of Maryland. As luck would have it, he sits on the Energy and Commerce Committee. If convinced of our story, he would play an important role in passing a companion bill in the House. My father (Steve Eller) would have to attend with me, but we were in! One small step...

On December 2, 2009 we were at the door of Congressman Sarbanes' office. Maryland families, who volunteered to help that day, stood with us. I entered the office to introduce myself. Within a few minutes, our entire group was welcomed to join. We had the ear of the Congressman's Health Legislative Assistant (LA), Dvora Lovinger - how exciting! After providing background information about PKU, medical foods, and our need for legislation, the Maryland families shared their stories and the struggles of fellow members of the PKU community. Their children also participated—what a wonderful impression they made! I felt positive about the meeting, but I wondered if we were direct enough about our need for the congressman's leadership and early support. My father and Sean Harrigan (both MD residents) returned to the office to say thank you and reiterated our need for help—how brave!

The next day, my father followed up with a call to the LA. I called and spoke to her as well, as I waited to board a plane back to Atlanta. Betsy Emerick, Maryland's dietician of many years, also placed a call. The following week, I sent a thank you note.

Over the next two and half months, I followed up with phone calls and emails. I wanted to be sure Congressman Sarbanes had the latest list of endorsing organizations and was kept up to date on progress. In doing this, I was able to develop a relationship with Dvora. Throughout the process, I felt grateful for her interest and expressed my thanks often.

## Did You Know..?

Georgia PKU Connect is more than 100 members strong! Join us today! Membership is free. Visit [www.georgiapku.org](http://www.georgiapku.org) for more details.

**JOIN US!**  
become a  
member  
today

# "High Hopes"

THE NATIONAL PKU ALLIANCE CONFERENCE

By Cynthia Hunt, Atlanta

My husband Steve and I are the proud Grandparents of Lucas who is 7 years old (CPKU) and we were fortunate to be able to attend the first National PKU Conference in Dallas, Texas.

The Conference was so well orchestrated, with very interesting speakers on a wide range of topics including ongoing PKU research in the areas of treatment, managing the PKU diet, new low-protein foods, and promising research that could lead to a cure. Video recordings of all these presentations can be viewed on line by accessing the National PKU Alliance website at [www.NPKUA.org](http://www.NPKUA.org) and I would really recommend that you find the time to watch these presentations to get a feel of the scope of the research and the number of wonderful people that are dedicated to making life easier for PKU families.

Over 330 people attended the Conference and we met so many wonderful people from PKU families from across the USA, and also from Canada, Australia and Germany. All had many interesting stories to tell about their own experiences living with PKU but above all it was a wonderful experience to be there as a part of a large group of people who all have so much in common. I especially enjoyed meeting with Debbie from Australia who was the first child in that Country to be treated for PKU with a low protein diet.

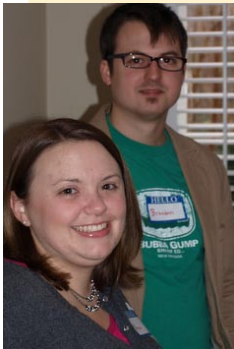
On Saturday there were group break-out sessions with different topics to choose from, such as Managing PKU at school, "Grand-power" for PKU grandparents, Fund raising etc. I attended the session on Fund Raising and found it very informative, especially discussing with people from other states the various projects they sponsor. Several states hold summer camps for the PKU families which sounded a lot of fun with various activities as well as an extended education program. We came back home wondering how could we get involved in establishing a PKU summer camp for Georgia.

In summary, the first NPKU Conference was amazing, informative, inspirational and fun and we would like to thank the National PKU Alliance for organizing this great event. We met so many great PKU families and we came away from the conference reassured that many significant activities are underway to make things better for all of us in the PKU community. By coming together as a National organization for PKU we are becoming a powerful force to advocate necessary changes in insurance coverage and focus PKU research towards a cure.

**Want to ask your Senators and House Representative to support the Medical Foods Equity Act, but you're not sure who they are?**

Go to [www.senate.gov](http://www.senate.gov) (select "Georgia" or your home state) and [www.house.gov](http://www.house.gov) (enter your zip code + 4 digits) for contact information. Visit [www.georgiapku.org](http://www.georgiapku.org) for talking points.

**Together we can have a strong voice!**



Photos on this page are from the many GA PKU events this past Fall and Winter, including the BioMarin Town Hall meeting at the Chattanooga Aquarium and the Holiday Meet and Greet at the Vanags' home.