



The National PKU Alliance is thrilled to share some very exciting news with you!

Greetings!

As many of you have heard, the NPKUA made a strong advocacy push this summer in Washington D.C. and in our home states. Multiple adults with PKU, along with parents and grandparents of children with PKU, lobbied members of the House and Senate to share the compelling need for federal laws to ensure that children and adults with PKU, and 29 other inborn errors of metabolism, have affordable access to the treatment needed to lead healthy productive lives.

Dozens of families and individuals with inborn errors of metabolism continue to submit their very personal and painful stories of struggling to get insurance coverage for the treatment they desperately need. These poignant stories have come in from across the country and help to show the struggles are far reaching and incredibly real. Clinicians, dietitians, and geneticists from across the country have been providing letters and documents to help drive the effort. Family members, co-workers, and friends have sent e-mails to Congress voicing their support.

I am pleased to announce that your hard work and High Hopes have paid off!

Senator John Kerry from Massachusetts announced on September 01, 2009 that he is drafting legislation to federally mandate insurance companies to cover medical food and formula treatment for thirty inborn errors of metabolism, including PKU! The final draft of the legislation is being written, and Senator Kerry will be introducing the legislation on the floor of the Senate soon. We will release details of the proposed bill as soon as they are available.

Thank you everyone who is helping with this bold and ambitious effort!

Please be thinking of creative ideas on how we can collectively thank Senator Kerry and his staff for making this a priority and for taking the leadership reins. Also, please continue to reach out to your Senators and House Representatives and let them know that we'll need co-sponsors and their support to help get the bill passed.

The NPKUA will keep you updated with the details as they develop.

With High Hopes and Goodwill,

~Kelly McDonald
Advocacy Chair, NPKUA