



National
PKU
Alliance

research | education | support | advocacy

Kristen Vanags

Advocacy Committee Representative



Our Mission

To improve the lives of individuals and families with PKU through research, support, education and advocacy, while ultimately seeking a cure.

Medical Foods Advocacy

- ▶ Newborns are screened for inborn errors of metabolism, but treatment for such conditions is not uniformly covered by insurance
- ▶ 38 states have some legislation for medical foods
- ▶ Provisions are inconsistent and many self-insured plans deny treatment under ERISA

The cost of treating an individual with untreated PKU can be up to 13 times the cost of providing proper treatment

Medical Foods Advocacy

- ▶ The Patient Protection and Affordable Care Act (PPACA)
 - Signed into law on March 23, 2010
 - Benefits and Regulation Opportunities

- ▶ Medical Foods Equity Act (MFEA)
 - Senate Bill (S.2766), Kerry (MA), Nov. 10, 2009
 - House Bill (HR.4926), Baldwin (WI-2), March 24, 2010

Immediate PPACA Benefits

- ▶ Children with pre-existing conditions can no longer be denied health insurance coverage
- ▶ All Americans who are uninsurable because of a pre-existing condition will have access to insurance through a state administered temporary high-risk pool - www.healthcare.gov
- ▶ Private health insurance exchanges will address this segment by 2014

Additional PPACA Benefits

- ▶ Insurance companies will be banned from placing lifetime or annual limits on coverage or canceling coverage due to illness
- ▶ Extends Coverage for Young People up to their 26th Birthday through Parent's Insurance
- ▶ By 2014, Medicaid coverage will be expanded to those under 133% of the Federal Poverty Level, or \$14,404 for an individual and \$29,327 for a family of four

Influencing PPACA Regulation

- ▶ Inspire HHS to regulate the bill equitably
- ▶ Ensure the “high risk pool” includes PKU and other Inborn Errors of Metabolism
- ▶ Include Medical Foods as Essential Health Benefits
- ▶ Other Opportunities?

The Medical Foods Equity Act

Although Newborn Screening requires states to screen, there is not adequate coverage for required treatments.

- ▶ Addresses coverage of medical foods for life
- ▶ Based on recommendations of the HHS Advisory Committee on Heritable Disorders in Newborns and Children
- ▶ Endorsed by over 40 organizations
- ▶ Covers 29 Inborn Errors of Metabolism (IEMs)

The Medical Foods Equity Act

- ▶ Requires coverage by all private insurance plans and federal health programs
- ▶ Health insurance plans governed by ERISA would not be exempt
- ▶ HHS would determine the minimum yearly coverage for all health insurance plans
- ▶ Would not pre-empt state standards that require a higher minimum standard
- ▶ Protects access to treatment – North Carolina

The Medical Foods Equity Act

www.thomas.gov

HR 4926 IH

111th CONGRESS

2d Session

H. R. 4926

To provide for the coverage of medically necessary food under Federal health programs and private health insurance.

IN THE HOUSE OF REPRESENTATIVES

March 24, 2010

Ms. BALDWIN (for herself, Mr. EDWARDS of Texas, Mr. POLIS of Colorado, Mr. SARBANES, and Mr. JOHNSON of Georgia) introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committees on Ways and Means, Education and Labor, and Armed Services, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

Advocacy in Action

- ▶ Collaboration with Clinicians, Patient Support Organizations and Industry
- ▶ Community Awareness Campaigns
- ▶ Emails, Calls, District and Capitol Hill Visits
- ▶ Media



Move for Medical Foods

Anna Parker's Advocacy Story
Capitol Hill, June 9-11, 2010



Congressman Paul Broun's
Office, Georgia 10th District



United States Capitol
Kristen and Anna

**House Bill (HR. 4926) and Senate Bill (S.2766) Need
Co-Sponsors to Pass!**

How you can help!

- ▶ Equip yourself and others, www.npkua.org
- ▶ Call and email your legislators... Again
- ▶ Visit Members of Congress in-district
- ▶ Write Letters-to-the-Editor, Contact TV News
- ▶ Enlist the help of everyone you know!



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*Together...
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change
history.*

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678-612-8408

kristen@georgiapku.org

www.georgiapku.org

www.npkua.org