



## Medical Food Equity Act Senate Bill Advocacy Guide

**Our community needs as many co-sponsors as possible in the U.S. Senate for the Medical Foods Equity Act (S. 2766)! Even if you currently have coverage for your medical food (formula) and/or low-protein foods, please take a few moments to make a difference for the many that are struggling with access to treatment. Let's work together to make history!**

**The Medical Foods Equity Act would require ALL insurance companies to cover the cost of medical foods (both formula and food modified to be low in protein) for CHILDREN AND ADULTS with PKU and other inborn errors of metabolism. This includes federal insurance programs, such as Children's Health Insurance Program, Tricare, Medicaid and Medicare.**

**The following steps can be taken to successfully advocate for S. 2766.** At anytime, you can contact Kristen (678-406-9162, [kristen@georgiapku.org](mailto:kristen@georgiapku.org)), Amy (801-277-3808, [amy@go-ipad.org](mailto:amy@go-ipad.org)), Kelly (254-366-3256, [kelly.mcdonald@npkua.org](mailto:kelly.mcdonald@npkua.org)), Christine (715-437-0477, [christine.brown@npkua.org](mailto:christine.brown@npkua.org)) or Abigail (715-437-0478, [abigail.bostwick@npkua.org](mailto:abigail.bostwick@npkua.org)) for assistance. We are happy to help you!

**PLEASE GO TO <http://www.npkua.org/index.php/your-legislators> and lookup your two congressional members in the U.S. Senate. Make note of your SENATOR'S NAMES and WASHINGTON D.C. PHONE NUMBERS.**

- 1. As soon as possible, call their Washington D.C. offices and ask to speak with their Health Legislative Assistants.**
- 2. Use the guide below to explain the reason for your call.**

Thank you for taking the time to speak with me. My name is \_\_\_\_\_ and I am calling to talk with you about the Medical Foods Equity Act (S. 2766) introduced by Senator John Kerry. *Feel free to provide your relation to the PKU Community.*

- 3. Before going further, ask the Health LA if they are familiar with PKU. If not, provide the following information:**
  - PKU is an inherited metabolic disorder in which the body cannot process a part of protein called phenylalanine.
  - Untreated PKU can lead to severe, progressive mental retardation.
  - In order to remain healthy, individuals with PKU are limited to a highly restrictive low-protein diet and must consume medical food every day for the rest of their lives.
- 4. Explain why the legislation is needed.**
  - Although the Newborn Screening Saves Lives Act requires states to screen for PKU, there is not adequate coverage for the required treatment.

- 38 states have laws governing medical foods, but they are inconsistent and many patients are denied access to treatment. **In states with treatment provisions, 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 are expensive because they are manufactured for treatment of rare conditions. The average family cannot afford them without insurance coverage or other assistance.
- The FDA definition of medical food is "a food which is formulated to be consumed or administered enterally under the supervision of a physician and which is intended for the specific dietary management of a disease."
- The Medical Foods Equity Act is based on recommendations of the HHS Advisory Committee on Heritable Disorders in Newborns and Children and endorsed by over 40 organizations.
- States screen for disorders in order to prevent the complications of treatable conditions. Ensuring adequate insurance coverage is a logical extension of the Newborn Screening system.
- The recently passed health care reform bill does not include PKU and other inborn errors of metabolism in the high risk pool, nor are medical foods listed as essential health benefits.

**5. Explain why co-sponsorship is the right thing to do.**

- An untreated child with PKU can lose 4 IQ points each month and will become severely mentally retarded before reaching toddlerhood.
- Children and adults who are off-diet also experience many other medical issues, including depression, impulse control disorder, phobias, epilepsy, tremors, and pareses.
- Women with PKU face a special dilemma in planning a pregnancy. Infants of mothers with high phenylalanine levels exhibit mental retardation, heart defects, and growth retardation.

**6. Thank the Health LA for taking the time to speak with you and request their email address. Ask when they will be able to provide feedback from your Senator.**

**BONUS ACTIVITY: If you are willing, ask if you can schedule an in-district appointment with your Senator or a constituent liaison.**

**7. Within 3-4 days send a thank you email to the Health LA with YOUR NAME, ADDRESS and PHONE NUMBER.**

Reinforce your request for co-sponsorship for The Medical Foods Equity Act (S. 2766).

ADVOCACY TIP: Go to: <http://www.npkua.org/index.php/talking-points> and download the [HHS Medical Foods Recommendations](#), [Medical Foods Equity Act Legislative Outline](#), and the [Medical Foods Equity Act Endorsing Organizations list](#) and attach them to your thank you email. Ask them to review the attachments in your message.

**8. Email the PKU Listserv or [kristen@georgiapku.org](mailto:kristen@georgiapku.org) to let us know how you're doing! Use the subject line PKU Advocacy – YOUR SENATOR’S NAME.** The NPKUA Advocacy committee is so proud of our strong community and is committed to supporting your efforts for all children and adults with PKU!

## **SEND A LETTER TO YOUR LOCAL PAPER(S)**

1. Download copies of the Medical Foods Equity Act Sample Letters here:  
<http://www.npkua.org/index.php/talking-points>
2. Make modifications to one of the samples and send to your local paper(s) – it's that easy!
3. Pat yourself on the back – you are doing a great job advocating for PKU!

**ASK FRIENDS AND FAMILY MEMBERS to call their Senator's offices and request support. Send them a message using the following template:**

Dear Friends and Family,

I need your help to raise awareness for PKU and identify co-sponsors for the Medical Foods Equity Act (S. 2766) in the U.S. Senate. This is an important bill that will ensure ALL insurance plans provide coverage for the treatment of PKU and other Inborn Errors of Metabolism.

*Feel free to add a personal message.*

You can look up your two Senators here: <http://www.npkua.org/index.php/your-legislators>

Please call their Washington D.C. offices and use the script below to leave a message with the individual who answers the phone.

My name is \_\_\_\_\_ and I would like to urge Senator \_\_\_\_\_ to support and co-sponsor The Medical Foods Equity Act (S. 2766). This legislation will improve lives and save healthcare dollars. Please pass along my message to Senator \_\_\_\_\_ and his/her Health Legislative Assistant. I am happy to provide my address so Senator \_\_\_\_\_ can provide his position. Thank you for your time and have a wonderful day.

**Thank you for your help. I am happy to answer any questions about the Medical Foods Equity Act.**

Sincerely,

[Your Name]

## **CALL YOUR SENATOR'S OFFICES TO FOLLOW UP**

1. Call their Washington D.C. offices and ask to speak with their Health Legislative Assistants.
2. Use the guide below to explain the reason for your call.

My name is \_\_\_\_\_ and I am calling to follow up on our discussion a few weeks ago regarding the Medical Foods Equity Act (S. 2766). I am hoping Senator \_\_\_\_\_ has decided to be a co-sponsor.

3. Email the PKU Listserv or [kristen@georgiapku.org](mailto:kristen@georgiapku.org) and let us know the status of your Senator's support! Use the subject line PKU Advocacy – YOUR SENATOR'S NAME.

**Thank you so much for your enthusiasm and dedication to our community!**