Help us build support for the Medical Nutrition Equity Act in the U.S. Senate and House of Representatives!

The Medical Nutrition Equity Act would provide public and private insurance coverage for physician prescribed medical foods - medical formulas and low protein modified foods for children and adults with PKU and other inborn errors of metabolism.

Taking action is quick and simple.


2. Call your Senator’s and Representative’s offices and ask to speak with the health legislative assistant - *If you are transferred to voicemail, leave a brief message – include your name and number, so they can return your call.*

3. Introduce yourself and let them know you are contacting them about the Medical Nutrition Equity Act (H.R. 2587 and S. 1194). This bill is sponsored in the Senate by Senator Bob Casey and co-sponsored by Senator Chuck Grassley; and sponsored by Representative John Delaney and Representative Jamie Herrera Beutler in the House.

4. Explain you are calling as a member of the PKU community and need your Senator/Representative to support the Medical Nutrition Equity Act (H.R. 2587 and S. 1194) and sign on as an original co-sponsor.

5. Let them know the Medical Nutrition Equity Act (H.R. 2587 and S. 1194) would provide public and private insurance coverage for the medically necessary treatment for PKU – medical formulas and low protein modified foods, which are required to prevent severe disability.

6. Share your personal connection to PKU and why treatment coverage is so important. Consider the following talking points:
   - Phenylketonuria (PKU) is a rare, inherited metabolic disorder (or inborn error of metabolism) in which the body cannot process a part of protein called phenylalanine.
   - The United States has screened newborns for PKU since 1963. Although law requires every state to screen newborns, there is not adequate coverage for the required treatment.
   - Specialized medical foods (physician prescribed medical formulas and low protein modified foods) are required for the safe and effective management of PKU and other inborn error of metabolism diagnosed through newborn screening.
   - Without early and continuous PKU treatment, sustained high levels of phenylalanine causes intellectual disabilities and other serious health problems.
   - Adults with PKU who discontinue treatment or at risk for serious medical issues, such as depression, impulse control disorder, phobia, tremors, and pareses.
   - Women with PKU must maintain strict metabolic control before and during pregnancy to prevent fetal damage. Children born from untreated mothers with PKU may have a condition known as “maternal phenylketonuria syndrome”, which can cause small brains, intellectual disabilities, birth defects of the heart, and low birth weights.
• The medical foods required to treat PKU cost approximately $12,000 - $15,000 per year, which is far beyond the means of most every PKU family. The cost of not treating PKU, however, is much greater. Caring for an untreated PKU patient is at least 8 times more expensive.

• The American Medical Association recently passed a resolution in support of legislation requiring insurance coverage for specialized medical food products used to treat 28 inborn errors of metabolism, including PKU.

7. Before finishing up the call, let them know how much you appreciate their time. Ask for their email address, so you can follow up with them in the next couple of days.

8. Shortly after your phone conversation (within a week), send the legislative assistant a kind message thanking them again for speaking with you. Let them know how important the Medical Nutrition Equity Act (H.R. 2587 and S. 1194) is to you/your family and ask if your Senator/Representative will support the bill and sign-on as a co-sponsor. Include links to the following documents in your email:

• Medical Nutrition Equity Act Two-Pager
• American Medical Association Resolution - Health Coverage for Nutritional Products for Inborn Errors of Metabolism (Inherited Metabolic Disorders)
• Genetic Metabolic Dieticians International Position Statement on Medical Foods
• Senate Resolution 627 Designating December 3, 2016 as National Phenylketonuria Awareness Day
• Summary of Medical and Dietary Guidelines for the Treatment of PKU
• Full Medical Guidelines for the Treatment of PKU

Thank you for your advocacy efforts! Together we can make a difference for PKU!

Please feel free to contact Kristen Vanags at kristen@georgiapku.org or 678-612-8408 with any questions.