

To customize the template, simply replace the text in the brackets and delete the instructions.

Letters can be sent via email to the Health Legislative Assistant working in your Senator or House Representative's office (if you call the member's DC office phone number, they will be happy to give you the HLAs name and email address) or you can FAX your letter to the member's D.C. office. If you want to make sure your letter is received, feel free to send it via email and FAX. The content of your letter can also be pasted into online contact forms on member websites – you may not be able to include a photo, but sending a letter this way is great too!

IMPORTANT: In addition to sending your letters personally, please consider sending a copy to the NPKUA, so we can bundle the letters together and deliver them to Congress. Letters can be sent to: katrina.swenson@npkua.org

For contact information and website links for your two Senators and House Representative visit <https://www.npkua.org/Take-Action/Your-Legislators>. Many members of Congress are waiting to receive letters from their constituents before co-sponsoring. Thank you so much for your help!

[Date]

[The Honorable (First Name Last Name of Senator or Representative)]

[United States House of Representatives or United States Senate]

[(Office Number and Building Name) Office Building]

[Washington, DC (Zip Code)]

Dear [Senator _____ or Representative _____]

I am writing to ask for your support co-sponsoring the Medical Nutrition Equity Act (H.R.2587 and S.1194). [Add your relationship to PKU and why this legislation is important to you. For example, I am the parent of child with Phenylketonuria. My son/daughter is __ years old and requires treatment with medical formulas and low protein modified foods. Without these medical foods, my child will have brain damage and experience serious neurological complications. OR I have a medical condition called Phenylketonuria. Without treatment with medical foods, I...(explain what would happen to you without PKU formula and low protein modified foods or what is happening to you if don't currently have coverage). OR I am the aunt/uncle/cousin/grandparent/friend of a child/individual with Phenylketonuria and making sure they have the treatment they need to prevent brain damage and other serious neurological complications is very important to me. Feel free to customize this section to work for your personal situation or relationship to PKU.]

Co-sponsorship is the right thing to do. [Pick 3 or more points to include below.]

- 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.
- An untreated child with PKU can lose 4 IQ points each month and will become severely intellectually disabled before reaching toddlerhood.
- Adults with PKU who discontinue treatment are 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.

To co-sponsor this important bi-partisan legislation, please feel free to reach out to any of the following individuals:

Sara Maskornick (sara_maskornick@casey.senate.gov) with Senator Casey
Karen Summar (karen_summar@grassley.senate.gov) with Senator Grassley
Lauren Santabar (lauren.santabar@mail.house.gov) with Rep. Delaney
Anna Breen (anna.breen@mail.house.gov) in Rep. Herrera Beutler

Thank you for your attention, and I hope I can count on your support. If you have any further questions please feel free to contact me.

Best regards,

[Your Name]
[Your Address]
[Your City, State, Zip]
[Your Email]
[Your Phone Number]

[Paste in a photo of yourself, your family, child, or friend with PKU. Resize and reposition your picture as needed. Feel free to add a caption.]