

ADVOCACY
= TELLING
YOUR
STORY



NATIONAL
PKU News

The Medical Nutrition Equity Act (MNEA)

Current Status of the MNEA

- **116 co-sponsors total**
 - [Senate](#): 22 (17D, 4R, 1I)
 - [House](#): 94 (79D, 15R)

**** NEED MORE REPUBLICAN CO-SPONSORS**
- **3-pronged approach for advocacy**
 - **PPMNE** (Patients and Providers for Medical Nutrition Equity group of 45 allied orgs)
 - **Crossroads** (NPKUA-contracted lobbying firm)
 - **Grassroots (You).**
- **The time is NOW.** We are actively working to push the bill through before the end of the year. If it doesn't pass by December we will need to reintroduce in January.

Opportunities for Legislative Advocacy

- **Rare Across America** - if you registered you will receive an email with your appointments. If you haven't yet, search your inbox for an email from advocacyday@advocacyassociates.com
- **Find + call your Senator / Rep** on <https://nutritionequity.org/find-your-representatives/> use your talking points (coming in next slides.)
- **Email your Senator + Representative** - <https://nutritionequity.org/contact-congress/>
- **Request in-district meetings with your Representatives / Senators during August recess.**

Republican Talking Points

- This legislation allows patients to choose treatment options that are medically appropriate for them based on their specific needs in conjunction with their physician.
- TRICARE's coverage of medical foods has already set the precedent for national coverage. Coverage has been made a priority for out military and should be a priority for all Americans.
- Children get this disease through no fault of their own and it represents a significant financial burden for families; medical foods cost as much as five times the cost of food.
- The financial strain on families to afford this food has only worsened with massive inflation, and these families, more importantly, their children, cannot afford to wait.

Democratic Talking Points

Not currently seeking more Democratic co-sponsors.

Ask your democratic legislators to speak to their colleagues on the other side of the aisle or suggest who you might speak with.

- There is no national mandate for coverage for medical foods, which is sometimes the only available effective treatment for PKU.
- Passing this bill is an effective step toward continuing to realize the full intent of the Affordable Care Act: affordable, accessible care for all Americans.
- There are many state mandates for coverage, but they are disparate and not uniform, meaning that a family could move from one state to another without realizing they could lose coverage for medical foods for themselves or their child(ren). Any self-insured plan (40-60% of private insurance) is exempt from state mandates.
- State coverage mandates are often cut off at an arbitrary age, but children don't "grow out" of having PKU.

Advocacy Through the Media

- The formula crisis has represented a unique opportunity for those who rely on medical nutrition
- **Supply** is not the same as **ACCESS**
- Contact your local media and tell them the “formula crisis” will not end for our community until we have safe, reliable, and affordable ACCESS to medical nutrition

Sharing YOUR Story is
the most important
tool we have to get
the MNEA passed.

Telling YOUR Story

When you advocate you are sharing the knowledge of something you live with everyday with your Representatives and Senators.

They NEED you to show up and tell YOUR STORY. That's what advocacy is all about. You're actually helping them understand why this is so important and why they should pay attention.

Think of the tips on the right as a kind of blueprint for your storytelling, but make your appeal your own.

1. **What's your name? Where do you live?** *(they love hearing from their constituents + sharing your neighborhood is a great way to connect.)*
2. **What is your ask?** *(I want Senator NAME / Rep NAME to co-sponsor the Medical Nutrition Equity Act, Senate number: S2013, House number: H.R. 3783)*
3. **Why does this matter to you?** *(Describe your or a loved one's disease/disorder. How does this medically necessary treatment change your / their life? This is key.)*
4. **What does the legislation (MNEA) accomplish?** *(while medical foods have been used to treat PKU for more than 50 years many insurance companies will not cover them, the Medical Nutrition Equity Act would solve this.)*
5. **Thank them for listening + ask how you can follow up with them?** *(Immediately send them any relevant supporting documents they've asked for.)*
6. **Set a reminder to follow up in two weeks.**

For follow-up materials
or additional questions
please email us:

lillian@lillianisabella.com
sarah@pkunews.org

