THE PKU VOICE
THE IMPACT OF ADVOCACY

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AGENDA

Background
Advocacy
Plan of Action
Case Study
BACKGROUND
Medical Foods Coverage Today

- Federal and State Exchanges under the Affordable Care Act
- State insurance mandates on private insurers
- Federal insurance programs: Medicare, Medicaid, CHIP, and TRICARE
- NPKUA efforts to pass the Medical Nutrition Equity Act in Congress (formerly the Medical Foods Equity Act)
- Case Study – What one state did to fill the gaps
Affordable Care Act Exchange Plans

- Insurance mandates cover medical foods in 39 states that have insurance mandates.
- Coverage follows the specific state mandate.
- Some states without mandates may cover medical foods – be sure to ask!
Private Insurance Plans

• 39 states currently have state insurance mandates that require some private insurance companies to cover medical foods.

• State insurance mandates only apply to insurance plans regulated by states – this does not include ERISA or “self-funded” or “self-insured” plans.

• Each state’s law is different:
  – Some include both formula and low protein foods.
  – Some have age limits or dollar limits.
Federal Insurance Programs - Medicare

• Medicare is insurance for people over the age of 62 or who are disabled (as determined by the Social Security Administration).

• Medicare does not provide any coverage for medical foods as a general matter.

• In only a few cases, has Medicare provided coverage for formula.
Federal Insurance Programs - Medicaid

• You or your child may qualify for free or low-cost coverage through Medicaid.

• Some states expanded Medicaid eligibility in 2014, so you and/or your child may qualify even if you have been turned down for Medicaid in the past.

• Medicaid may not cover formula and low protein foods for adults. If you are over age 18 with PKU and eligible for Medicaid, contact your state Medicaid program to find out if it covers formula and low protein foods.

• More info: www.healthcare.gov/medicaid-chip/getting-medicaid-chip/
Federal Insurance Programs - CHIP

• Your child may qualify for free or low-cost coverage through the Children’s Health Insurance Program (CHIP) – income qualifications vary by state.
• CHIP provides coverage for formula.
• You can apply for and enroll in CHIP any time of year.
• If your child qualifies, coverage begins immediately.
• More info: [www.healthcare.gov/medicaid-chip/childrens-health-insurance-program/](http://www.healthcare.gov/medicaid-chip/childrens-health-insurance-program/)
Federal Insurance Programs - TRICARE

• TRICARE is insurance for members of the military and their family.

• TRICARE covers formula for military spouses with PKU and children of military members with PKU.

• People with PKU are generally not eligible to join the military.

• We need your help to ensure medically necessary foods language is included in the Fiscal Year 2017 National Defense Authorization Act (NDAA).
Medical Nutrition Equity Act

• The lead sponsor of the MNEA is U.S. Senator Bob Casey.
• The MNEA would require ALL insurance plans – private plans, exchange plans, and plans offered through state and federal insurance programs – to cover Medical Foods (formula and low protein foods) for Inborn Errors of Metabolism.
• Medically necessary foods for certain digestive disorders would also be covered.
• Treatment coverage would be provided regardless of age!
• The MNEA is a collaborative effort between the National PKU Alliance, American Academy of Pediatrics, and the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition
• More advocates means a greater likelihood for success!
ADVOCACY
What is advocacy?

• Advocacy is speaking and acting on behalf of yourself or others.
• Advocacy is educating people around you.
• Advocacy is simply telling your story.
How do I advocate?

• Take responsibility for telling people what you need, doing it in a straightforward way.
• Take a proactive role and speak up. If you don’t tell people what you or your loved one needs, they can’t provide it.
Why would I need to advocate?

- Advocacy is important because you and your loved ones are important!
- When you have PKU or have a loved one with PKU, you are the person with the best knowledge and experience about what you or your loved one needs.
- You are in the best position to communicate that information to people to get their support.
Advocacy with Congress

• In order to get the Medical Nutrition Equity Act passed and achieve better insurance coverage for Medical Food (formula and low protein foods), we all need to work together on the national level.

• We are in this together! As members of the PKU community, we can improve insurance coverage for everyone.

• We need everyone to contact their U.S. Senators and ask them to join as an original co-sponsor of the Medical Nutrition Equity Act.

• We can also contact U.S. House Members to ask for their support.
NDAA Action Alert

• The NDAA is an opportunity to improve TRICARE coverage, and it would be a big win for all of us!
• The Senate version includes important text requiring TRICARE to cover formula and low protein foods for PKU.
• The House version only includes a review of current coverage.
• A Conference Committee must reconcile the two bills before a final vote.
• If one of your congressional members is on the NDAA Conference Committee, we need you to contact their offices and ask them to support the medically necessary foods language in the Senate version NOW.
PLAN OF ACTION
Contacting Elected Officials

• Does your phone call, email, letter or visit really make a difference? YES!
• Your elected officials are there for you, their constituent.
• Elected officials make decisions based on what they believe their voters want.
How to Contact Elected Officials

Make a phone call!

- Contact your Congressional Members (everyone has one Rep. in the House of Representatives and two U.S. Senators)
- When you call, ask to speak to the Health Legislative Aide.
- Share your story. Tell them why coverage of PKU treatment is so important!
- Ask the elected official for help addressing access to PKU treatment (such as co-sponsoring the Medical Nutrition Equity Act or writing a letter to the Secretary of Health or Centers for Medicare & Medicaid Services).
- Thank them for their time.
- Follow up with a letter or email.
How to Contact Elected Officials

Write an email or letter!

• Review MNEA talking points.
• Identify yourself and your connection to PKU.
• Request that the elected official join as a co-sponsor for the Medical Nutrition Equity Act.
• Explain why the elected official should co-sponsor the MNEA.
• Thank the elected official for their consideration.
• Tell them that you look forward to their response.
How to Contact Elected Officials

Schedule a meeting!

- Every member of the House of Representatives and Senate has a local office in your state.
- Call the local offices and request a meeting.
- Before the meeting, review the MNEA talking points.
- Bring handouts and props (a can of formula).
- Tell the elected official or the staff member why they should co-sponsor the Medical Nutrition Equity Act.
- Thank them for their time.
- Follow up immediately with an email and then a letter.
How to Contact Elected Officials

• Key points to remember when communicating with elected officials and their staff:
  – They want to hear from you!
  – Tell them your personal story – this will have the biggest and most lasting impact.

• Contact us with any questions!
  – kristen@georgiapku.org
  – 678.612.8408
Tips for Success

• Plan ahead and focus on the goal
• Coordinate with stakeholders and constituents
• Schedule face-time whenever possible
• Clearly articulate the issue and manage the details
• Propose options, offer flexibility
• Be persuasive, tenacious, tactful, and charismatic
• Don’t take no for an answer
• Say thank you!
Everyone can make a difference!
CASE STUDY
Georgia
YOU CAN DO IT!