ADVOCACY
MEDICAL FOODS WEBINAR

Thursday, January 26, 2017
Topics: The NDAA, Medical Nutrition Equity Act, State Level Options, and Best Practices
NDAA/TRICARE Success!

• The Fiscal Year 2017 National Defense Authorization Act passed with medical necessary foods provisions for TRICARE!
• TRICARE currently covers medical food “formula” and will soon cover low protein modified foods
• Coverage by TRICARE will set an important precedent for other federal programs
• Thank you so much for speaking up for PKU!
Status of the MNEA

• The Medical Nutrition Equity Act is drafted and we need your help to find a republican co-sponsor
• Passage would require all private and public insurance plans to cover formula and low protein modified foods for CHILDREN AND ADULTS
• Advocacy resources are available @ https://www.npkua.org/Take-Action/Medical-Nutrition-Equity-Act
• Let’s check them out!
State Mandates

• Review current “Statutes & Regulations on Dietary Treatment of Disorders Identified Through Newborn Screening” @ http://cahpp.org/resources/dietary-treatment-statutes, identify opportunities to improve coverage in your state, and take action!

• Build a strong local advocacy team

• Reach out to the NPKUA, your local PKU organization, NORD’s Rare Action Network (http://rareaction.org/), Rare Disease Legislative Advocates (http://rareadvocates.org/), and others for help!
State Budget Appropriations

• Are you having trouble passing a mandate?
• A state budget line item for medical foods assistance may be what you need!
• A handful of states provide PKU treatment through their annual budget
• Having a state funded assistance program is helpful even if your state has a strong mandate
• Self-insured plans to not have to follow state laws
Georgia Case Study

• No state level mandate, efforts to pass a mandate were unsuccessful

• Georgia PKU Connect proposed an increase to the state NBS fee (with support from Georgia’s NBS Advisory Committee) to fund medical foods assistance

• A multi-year advocacy effort resulted in a $1.2 million annual public health grant awarded to Emory to implement and manage the program

Emory Metabolic Nutrition Program awarded $1.2M for nutrition therapy program for inherited metabolic disorders

Georgia PKU Connect celebrates life-saving grant funding for Georgians with rare inherited metabolic disorders (IMD) diagnosed through newborn screening
Why we were successful

- Collected data from other states with medical foods assistance
- Created a solid estimate on cost per year based on Georgia’s inherited metabolic disorder population and coverage gaps
- Made the case for access to treatment
  - Georgia NBS Statute includes “initiating and continuing therapy” as a key component of the NBS System
  - Our NBS fee was low, room to go up
  - Not treating NBS conditions results in disability and death
  - Too many Maternal PKU Syndrome cases in Georgia
  - Cost saving and the right thing to do!
Why we were successful

• We were relentless, face-to-face meetings with the House Insurance Committee Chairman and Appropriations Committee Members were key – we were kind, but would not take no for an answer

• Ensured the line item wording included adults: Provide funds for therapies for individuals with congenital disorders pursuant to O.C.G.A. 31-12-6

• Provided status to local advocates, metabolic clinic, public health officials throughout the process – asked for their help and participation along the way to strengthen our advocacy efforts
Best Practices

• 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 – check out these Tips On How To Contact Congress
• Don’t take no for an answer
• Say thank you!
2017 Priorities

• Advocate for key provisions of the ACA (always highlighting the need for gaps in medical food for NBS conditions to be addressed)

• Work with Congress to resolve medical foods coverage gaps in federal programs

• Assist with state level efforts to pass or improve mandates – VA, ND, others as local advocates identify opportunities

• Continue to encourage members of Congress to support the MNEA
Lobby Days in May

• The NPKUA will head to Capitol Hill to meet with legislators May 22nd and May 23rd

• We look forward to having advocates from all over the country join us!

• Even if you’re not able to travel to D.C., you can setup meetings with your House Representative and Senators for us to attend on your behalf

• Lobby days are a great way to make the PKU voice heard in Congress!
YOU CAN DO IT!
Contact Us

Let us know if you have any questions!

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