



# ADVOCACY

## MEDICAL FOODS WEBINAR

**Thursday, January 26, 2017**

Topics: The NDAA, Medical  
Nutrition Equity Act, State Level  
Options, and Best Practices

# NDAA/TRICARE Success!

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- 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

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- 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

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- 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

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- 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 do not have to follow state laws

# Georgia Case Study

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- 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

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- 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

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- 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

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- 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

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- 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

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- The NPKUA will head to Capitol Hill to meet with legislators May 22<sup>nd</sup> and May 23<sup>rd</sup>
- 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

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Let us know if you have any questions!

- **Kristen Vanags, NPKUA Advocacy Chair**  
kristen@georgiapku.org, call or text 678-612-8408
- **Amy J. Oliver, J.D., NPKUA President**  
amy@go-ipad.org
- **Christine Brown, NPKUA Executive Director**  
christine.brown@npkua.org