

# TALKING WITH MEDIA ABOUT THE FORMULA CRISIS

*From the perspective of the IEM Community*

## Your personal story is most important

- How is this affecting you and your family physically, psychologically, and financially?

## It's not just baby formula

- Thousands of infants, older children, and adults require formula as their primary medical treatment for their entire lives
- Formula can comprise as much of 80% of an individual's nutrition
- Formula is essential to prevent disability, brain damage, and in some disorders, death
- Maternal PKU Syndrome causes serious birth defects and may occur in pregnant women with PKU due to insufficient medical nutrition

## It's not just PKU

- There are many Inborn Errors of Metabolism which require medical formulas to treat, some of which can have incredibly severe outcomes in the face of insufficient medical nutrition
- Many of these disorders are detected by Newborn Screening on the premise that we have the means to treat them (medical nutrition)

## We can't just switch brands

- Inability to tolerate a new formula may result in serious medical consequences
- People have grown accustomed to these formulas over years, and decades
- Many brands are now backordered due to a domino effect in the sector

## The uncertainty is adding to the burden of managing these complex medical conditions

- We need clarity from the FDA on their timeline for clearing the Abbott plant for manufacturing, and from metabolic formula companies on the status of their manufacturing capacity and supply chain

## This crisis won't end until we pass the MNEA

- Thousands of Americans don't have access to medical nutrition even when there are no shortages because laws governing medical nutrition coverage are inadequate & discriminatory, an unacceptable & constant risk to their health.
- The Medical Nutrition Equity Act (HR3783/S2013) is a bi-partisan, bi-cameral bill whose provisions were codified for TRICARE in the Defense Reauthorization Act of 2017