

## Statement from Inherited Metabolic Disorder (IMD) Community Leaders on COVID-19 and the Medical Nutrition Equity Act

March 31, 2020

On March 12, 2020 the CDC announced a list of those at increased risk during the COVID-19 pandemic, including those with inherited metabolic disorders (IMD). These disorders are among the core conditions whose treatment needs are addressed by the Medical Nutrition Equity Act.

While The Medical Nutrition Equity Act is designed to establish a federal floor to provide coverage equity to those who *currently have inadequate medical nutrition coverage*, the current global pandemic reveals the insecurity of **all** those who rely on medical nutrition, even those who currently have coverage:

- Supply-chain interruptions pose a threat to those who rely on medical nutrition every single day. Even small delays in insurance approval or pre-authorization may be compounded by supply-chain delays, resulting in inadequate medical nutrition.
- Medical nutrition coverage provided through employer-provided healthcare may not be available to those who are furloughed and laid-off due to state-mandated business closures during pandemics
- Those who lose private insurance coverage will not have access to the medical nutrition they need, resulting in immediate and permanent damage to their health.
- Those who lose private insurance and enroll in public programs face delays for enrollment, pre-authorization, and the standard struggles to obtain approval for medical nutrition.
- Public health systems may face a surge in enrollment, and a reduction of funding, which puts thousands of inherited metabolic disorder patients at risk.

**One day without medical nutrition harms the health of an individual with a metabolic disorder:** effects of insufficient medical nutrition can range from depression, anxiety, IQ loss, and inability to work, to metabolic decompensation, coma, and death. Therefore, swift passage of the Medical Nutrition Equity Act is critical to protecting these patients' lives during the Coronavirus pandemic.

We urge Congress to use every possible avenue to close the gaps in standard-of-care treatment access for medical nutrition and mitigate health risk for Americans with inherited metabolic disorders.

Christine S. Brown  
Executive Director  
National PKU Alliance

Sarah Chamberlin  
Executive Director  
National PKU News

Danae' Bartke  
Executive Director  
HCU Network America

Kathy Stagni  
Executive Director  
Organic Acidemia Association

Jordann Coleman  
Board Member - Advocacy Lead  
MSUD Family Support Group

Jon Miller  
President  
Network of Tyrosinemia Advocates

Deb Lee Gould  
Director  
FOD Family Support Group

-----

Please Contact Kylie Barber, Medical Foods Policy Fellow at the EveryLife Foundation, at [kbarber@curetheprocess.org](mailto:kbarber@curetheprocess.org) with any questions.