RESOLUTION 03-23

Title:	Newborn Screening for Urea Cycle Disorder
Introduced by:	Ashton Lewandowski, for the Medical Student Section
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Referred To:	Reference Committee D
House Action:	**APPROVED**

Whereas, urea cycle disorders are inherited metabolic errors that affect urea synthesis, and

Whereas, urea cycle disorders can cause high ammonia levels that are toxic to the brain (hyperammonemic encephalopathy), and

Whereas, these deficiencies have been identified in all urea cycle enzymes, and

Whereas, deficiencies of OTC and CPS1 enzymatic activities are the most common types of urea cycle disorders and can be debilitating and ultimately fatal if not detected within hours to days, and

Whereas, the incidence of urea cycle disorders is 1 in 8,200 births/year and the average birth prevalence is 1 in 35,000 per year, and

Whereas, the complications of urea cycle disorders can be lethal in 11 percent of patients in the first year of life and 31 percent of patients have a developmental delay, and

Whereas, relatively inexpensive blood ammonia tests ($59) can be used to diagnose urea cycle disorders within minutes, and

Whereas, 10 states require CPS1 deficiency screenings and 8 states require OTC deficiency screenings, and

Whereas, including urea cycle disorders in the newborn screening could theoretically diagnose up to two-thirds of all patients, and

Whereas, early and ongoing treatments such as diets low in protein, arginine and citrulline supplements, dialysis, and liver transplants can lead to better growth and development; therefore be it

RESOLVED: That MSMS support newborn screenings for newborns born in the state of Michigan; and be it further

RESOLVED: That MSMS encourages the inclusion of urea cycle disorders specifically OTC and CPS1 deficiency in the newborn screening through blood nitrogen level or other similar tests.

WAYS AND MEANS COMMITTEE FISCAL NOTE: $1,000-$2,000

Relevant MSMS Policy:

Michigan Newborn Screening Program: Addition of Spinal Muscular Atrophy
MSMS supports the inclusion of spinal muscular atrophy in the Michigan Newborn Screening Program.

Relevant AMA Policy:

Standardization of Newborn Screening Programs H-245.973
Our AMA: (1) recognizes the need for uniform minimum **newborn screening** (NBS) recommendations; (2) encourages continued research and discussions on the potential benefits and harms of NBS for certain diseases; and (3) supports **screening** for critical congenital heart defects for newborns following delivery prior to hospital discharge.

Sources:

1. Urea cycle disorders: Clinical features and diagnosis. UpToDate. Updated March 3, 2021. Accessed February 16, 2023. https://www.uptodate.com/contents/urea-cycle-disorders-clinical-features-and-diagnosis
2. Inherited disorders of the urea cycle. AACC. Clinical Chemistry Trainee Council. Inherited Disorders of the Urea Cycle. American Association for Clinical Chemistry. Published December 2019. Accessed February 16, 2023. https://www.aacc.org/science-and-research/clinical-chemistry-trainee-council/trainee-council-in-english/pearls-of-laboratory-medicine/2019/inherited-disorders-of-the-urea-cycle
3. National Library of Medicine. MedlinePlus. Blood sugar test - blood. Updated November 11, 2021. Accessed February 16, 2023. https://medlineplus.gov/ency/article/003506.htm
4. National Library of Medicine. MedlinePlus. Hereditary urea cycle abnormality. Updated November 1, 2021. Accessed February 16, 2023. https://medlineplus.gov/ency/article/000372.htm
5. Vasquez-Loarte T, Thompson JD, Merritt JL 2nd. Considering Proximal Urea Cycle Disorders in Expanded Newborn Screening. Int J Neonatal Screen. 2020;6(4):77. Published 2020 Oct 8. doi:10.3390/ijns6040077