THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

January 4, 2023

Ned Calonge, MD, MPH
Committee Chairperson
Advisory Committee on Heritable Disorders
in Newborns and Children
5600 Fishers Lane
Room 18W68
Rockville, MD 20857

Dear Dr. Calonge:

I am writing to you in response to Dr. Powell's letter of June 7, 2022, which transmitted to me the recommendation by the Advisory Committee on Heritable Disorders in Newborns and Children (Committee) to add Guanidinoacetate Methyltransferase (GAMT) deficiency to the Recommended Uniform Screening Panel (RUSP).

I appreciate the Committee's systematic evidence review of the available data on GAMT deficiency, including an analysis of the potential net benefits of newborn screening for GAMT deficiency, the availability of treatment, and the capability of state newborn screening programs to screen and connect infants identified with GAMT deficiency to treatment and follow-up services. I reviewed the evidence the report describes indicating that early intervention improves developmental and neurological outcomes for infants with GAMT deficiency. After considering the utility of current screening technologies, treatment for GAMT deficiency, and the impact on public health systems, I accept the Committee's recommendation to expand the RUSP to include GAMT deficiency.

The addition of GAMT deficiency to the RUSP does not constitute a requirement for states to implement screening and is only a recommendation. In addition, I ask the Committee to provide a report to me within 5 years describing the status of state implementation of GAMT deficiency screening, potential barriers to treatment and to long-term follow up, and health outcomes.

My thanks to you and the members of the Committee for your work to improve the health of our nation's infants and children.

Sincerely,

/s/

Xavier Becerra