



THE SECRETARY OF HEALTH AND HUMAN SERVICES

WASHINGTON, D.C. 20201

July 1, 2024

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

Dear Dr. Calonge:

I have reviewed the recommendation by the Advisory Committee on Heritable Disorders in Newborns and Children (Committee) to add infantile Krabbe disease (low galactocerebrosidase [GALC] and psychosine $\geq 10\text{nM}$) to the Recommended Uniform Screening Panel (RUSP).

After considering the utility of current screening technologies and the impact on public health systems, I accept the Committee's recommendation to expand the RUSP to include infantile Krabbe disease (low GALC and psychosine $\geq 10\text{nM}$).

While the addition of infantile Krabbe disease (GALC and psychosine $\geq 10\text{nM}$) to the RUSP does not constitute a requirement for states to implement screening, under section 2713 of the Public Health Service Act, 42 U.S.C. § 300gg-13, as added by the Affordable Care Act, and implementing final rules, most group health plans and health insurance issuers are required to provide coverage without cost-sharing for evidence-informed preventive screenings for conditions that are included on the RUSP.

I ask the Committee to provide a report to me within 5 years describing the status of implementation of infantile Krabbe disease screening across the United States, potential barriers to treatment and ongoing disease management, and health outcomes of infants identified by newborn screening.

I thank 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