



THE SECRETARY OF HEALTH AND HUMAN SERVICES

WASHINGTON, D.C. 20201

August 2, 2022

Cynthia M. Powell, M.D., FACMG, FAAP  
Committee Chairperson  
Advisory Committee on Heritable  
Disorders in Newborns and Children  
5600 Fishers Lane  
Room 18W68  
Rockville, MD 20857

Dear Dr. Powell:

Thank you for your recent letter, on behalf of the Advisory Committee on Heritable Disorders in Newborns and Children (Committee), regarding the Committee's recommendation to add Mucopolysaccharidosis Type II (MPS II) to the Recommended Uniform Screening Panel.

I appreciate the Committee's systematic evidence review of the available data on MPS II that includes an analysis of the benefits and harms of newborn screening for MPS II, early treatment, and the capability of state newborn screening programs to screen and connect infants identified with MPS II to treatment and follow-up services. I reviewed the evidence the report describes on how early screening and treatment can lead to better quality of life for individuals with MPS II, with increased mobility and greater independence in conducting daily living activities. After considering the utility of current screening technologies, treatment for MPS II, and the impact on public health systems, I accept the Committee's recommendation to expand the Recommended Uniform Screening Panel to include the addition of MPS II.

The addition of MPS II to the Recommended Uniform Screening Panel 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 MPS II screening, access, and cost of treatment for infants diagnosed with MPS II and the impact on families due to the treatment periodicity.

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

Sincerely,

/s/

Xavier Becerra