

RARE → READY COALITION



March 30, 2026

The Honorable Abigail D. Spanberger
Office of the Governor
P.O. Box 1475
Richmond, VA 23218

The Rare & Ready Coalition and the rare disease community we serve support HB 433.

HB 433 provides a much-needed update to Virginia's newborn screening law to keep pace with medical advances. We commend Virginia for enacting legislation in 2025 to align its screening program with the Recommended Uniform Screening Panel (RUSP).

Unfortunately, shortly thereafter, the federal Advisory Committee on Heritable Disorders in Newborns and Children, which had guided RUSP inclusion, was terminated, creating serious uncertainty around the future review of screening conditions.

HB 433 establishes a process for considering non-RUSP conditions and creates a horizon-scanning mechanism to identify emerging conditions for state review. Every condition added to the newborn screening panel represents lives saved through earlier diagnosis and intervention.

Sincerely,
Rare & Ready Coalition Members