

**DATE:** May 13, 2020

**TO:** Executive Board  
Indiana State Department of Health

**FROM:** Eldon Whetstone, Assistant Commissioner  
Health and Human Services Commission

**SUBJECT:** Emergency Adoption of Newborn Screening Rule



The Indiana State Department of Health (ISDH) Maternal and Child Health program requests the Executive Board, at the Board's May 13, 2020 meeting, to emergency adopt an amendment to the newborn screening rule (IAC 3-3). The emergency rule shall be effective July 1, 2020.

The proposed emergency rule amendment adds three additional disorders to the newborn and infant screening panel and increases the newborn screening fee to cover the cost of the additional disorders. The proposed emergency rule amendment is attached.

During the 2019 Legislative Session, the Indiana General Assembly passed Senate Enrolled Act (SEA) 41, affecting newborn screening. SEA 41 added three new disorders, Krabbe disease, Pompe disease, and Hurler syndrome to the newborn screening panel effective July 1, 2020. ISDH is seeking to amend its rule to reflect these legislative changes. In addition, ISDH is seeking to increase the newborn screening fee to cover the cost associated with the additional disorders. All three conditions can be fatal and are contributors to Indiana's infant mortality rate. With early detection and rapid intervention, newborns with these conditions have a chance for a longer, and higher quality life.