

# Support HB 1006: Modernize Colorado's Newborn Screening Program

(Rep. Hamner/Rep. Liston & Sen. Gardner/Sen. Moreno)

All babies born in the United States receive newborn screening. Newborn screening helps in the early identification of potentially life-threatening genetic and metabolic conditions as well as hearing loss. The newborn screening program in Colorado is managed by the Colorado Department of Public Health and Environment (CDPHE). The newborn screening law has not been updated in nearly twenty years. A strong newborn screening program is critical to ensure that every baby in Colorado can reach their full potential.

## Strengthen Genetic and Metabolic Screening Program

- While there is a national advisory committee on newborn screening, states determine their specific programs. The U.S. Department of Health and Human Services' Recommended Uniform Screening Panel periodically adds new conditions that states can consider including in their newborn screening program. The bill requires CDPHE to annually review new recommended conditions, consider input from the medical community and other child health advocates, and add new conditions as deemed appropriate by the agency.

## Protect Timeliness of Screenings

- Babies are born every day of the week, throughout the year. The benefits of newborn screening are only available if it is done in a timely manner as early intervention and lifesaving measures may be necessary. State rule currently requires the lab to be open six days per week with exceptions for holidays and weekends. In the interest of saving more babies, the bill will update the statute to ensure the lab is open a minimum of six days per week every week of the year without exceptions.

## Define Follow-Up Program

- Many other states include definitions of newborn screening follow-up programs to direct the roles and responsibilities of primary care providers, pediatric subspecialty providers, and CDPHE who are all involved in newborn screening and have a role in ensuring that babies receive subsequent testing and diagnosis. The bill requires CDPHE to define and operationalize the details of follow-up through a rulemaking process.

## Enhance Newborn Hearing Screening Program

- In 2016, approximately 2,000 Colorado babies needed to be rescreened after failing the initial hearing screening and 160 babies were ultimately diagnosed with hearing loss. Unless accurate diagnosis and treatment begins before six months of age, life-long deficits in cognition, language and speech can be the result. The bill will update language to ensure a strong newborn screening program. Currently, there is no state funding dedicated to hearing screening. The bill will seek to ensure a stable funding source for hearing screening.

## Supporters

American Academy of Pediatrics, Colorado Chapter | Children's Hospital Colorado | Clayton Early Learning | Colorado Academy of Audiology | Colorado Association of Family Physicians | Colorado Children's Campaign | Colorado Speech-Language-Hearing Association | Denver Health | March of Dimes | Marion Downs Center | MEDNAX National Medical Group | National Jewish Health | Rocky Mountain Hospital for Children | The Resource Exchange | Thrive Skilled Pediatric Care | UC Health | University of Colorado School of Medicine

## Contacts:

Ed Bowditch, 303-489-8680 | Sara Odendahl, 303-506-2348 | Melissa Osse, 720-473-9399 | Benjamin Waters, 720-837-6726 | Jerry Johnson, 303-905-0227