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February 25, 2025

The Honorable Susan R. Donovan, Chair
House Committee on Health and Human Services
State House
82 Smith St.
Providence, RI 02903

H 5495 – An Act Relating to Health and Safety – Maternal and Child Health Services for Children with Special Healthcare Needs

Dear Chair Donovan:

Please accept this letter of support for H 5495, legislation that would authorize a midwife, nurse practitioner, or physician assistant attending a newborn child to cause that child to be subject to newborn screening tests for metabolic, endocrine, and hemoglobinopathy disorders, and other conditions for which there is a medical benefit to the early detection and treatment of the disorder, and an assessment for developmental risk. This act was introduced at the request of the Rhode Island Department of Health (RIDOH). The proposed legislation would also authorize RIDOH to promulgate rules and regulations for the storage, access, and use of residual newborn screening specimens and classify data as protected health information.

Newborn screening programs are a public health success story. RIDOH proposes to allow midwives, nurse practitioners, and physician assistants to complete newborn screening tests for metabolic, endocrine, and hemoglobinopathy disorders, and other conditions for which there is a benefit to the early detection and treatment of the disorder. Currently, only physicians are authorized to complete such testing. In particular, the bloodspot screen and pulse oximetry screen, which tests for critical congenital heart diseases, need to be completed within 24 to 48 hours after birth. Allowing midwives, nurse practitioners, and physician assistants to complete testing will help ensure that these screens are not delayed, particularly for those babies who are born at home.

The proposed legislation would also authorize RIDOH to regulate and protect the storage, access, and use of residual newborn screening specimens and classify data as protected health care information. Per the State's records and retention policy, dried bloodspots are retained for 23 years in Rhode Island. Bloodspots are retained for various reasons including verification of testing results, quality control and quality assurance, and additional testing to provide families with informative genetic knowledge.

State policies should have robust systems to protect the privacy and confidentiality of source individuals for residual dried blood spots. Any access to dried blood spot information should be permitted only with appropriate authorization and under carefully considered protections for privacy and other legal rights. Newborn screening saves and improves lives. I encourage your

favorable consideration of this important public health legislation.

Sincerely,



Jerome M. Larkin, MD
Director

CC: The Honorable Rebecca Kislak
The Honorable Members of the House Committee on Health and Human Services
Nicole McCarty, Esquire, Chief Legal Counsel
Lynne Urbani, Director of House Policy