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ACLU OF RI POSITION: AMEND

TESTIMONY ON 21-S 234, AN ACT RELATING TO NEWBORN SCREENING PROGRAM March 24, 2021

This bill would require the Department of Health to mandate the expansion of current newborn screening requirements to include, at a minimum, all newborn screening tests for all disorders and conditions listed in the federal Recommended Uniform Screening Panel. The ACLU of Rhode Island urges an amendment to the bill to ensure that it does not override the important principle underlying newborn screening that has been carefully baked into state law.

The statute at issue currently requires 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.” (emphasis added). The limitation contained in the highlighted language is an important one, as it prevents testing for illnesses for which early detection has no medical benefit. That is, it prevents wide-ranging genetic screening of infants minutes or hours after their birth. The results of a screening without such a limitation could unnecessarily reveal a child or parents’ confidential medical information in terms of genetic disorders, and infringe on a parent’s privacy by putting this information in the hands of the state. Newborn testing for conditions that an infant may be pre-disposed to but never contract places a child on a life sentence they may never meet. This raises serious civil liberties and ethical concerns.

Of course, nothing in state law prevents parents from requesting further testing if they so wish. But the current language of the statute provides an important safeguard for the privacy and children and parents. Having no expertise whatsoever in RUSP, we do not know whether it does, or would ever, include testing for disorders that fail to meet the state’s current criteria. But in the event it does, we firmly believe Rhode Island should retain the authority to reject it. We therefore urge an amendment to this bill to make clear that testing for disorders and conditions listed in RUSP shall be performed, but only if they comport with the state law’s current screening standard.

Thank you for considering our views.