

CHAPTER 296

AN ACT concerning screening for disorders in newborn infants and amending and supplementing P.L.1977, c.321.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. Section 1 of P.L.1977, c.321 (C.26:2-110) is amended to read as follows:

C.26:2-110 Findings, declarations relative to screening for disorders in newborn infants.

1. The Legislature finds and declares that:

- a. Newborn screening is an essential public health activity that strives to screen every newborn infant for a variety of congenital disorders, which, if not detected and managed early, can result in significant morbidity, mortality, and disability. The State's newborn screening system shall be a coordinated and comprehensive effort to provide education, screening, follow-up, diagnosis, treatment and management, and program evaluation activities;

- b. Ongoing advances in technologies and treatment modalities make it possible to screen newborn infants for a wide array of biochemical disorders. It is imperative that the State adjust its Newborn Screening Program to incorporate these biochemical disorders to ensure that the program remains at the forefront of these advances; and

- c. It is the intent of this act to protect the health and quality of life of newborn infants born in this State by enhancing the capacity to screen for congenital disorders and by providing: all newborn infants with screens for certain conditions and with appropriate referrals and early medical intervention when warranted; and newborn data collection is standardized, and conditions detected by newborn screening are tracked and monitored. Further, information on newborn screening and conditions for which a newborn can be screened should be readily accessible, current, and understandable to both health care providers and parents or guardians.

C.26:2-110a Newborn Screening Advisory Review Committee.

2. The Commissioner of Health shall establish a Newborn Screening Advisory Review Committee to annually review the disorders included in the Newborn Screening Program, screening technologies, treatment options, and educational and follow-up procedures. The committee shall include, but need not be limited to, medical, hospital, and public health professionals, scientific experts, and consumer representatives and advocates. The committee shall meet annually to review and revise the list of disorders recommended for inclusion in the Newborn Screening Program. The committee shall allow for public input in the course of conducting its review and issue recommendations to the commissioner on the improvement of the Newborn Screening Program.

3. Section 2 of P.L.1977, c.321 (C.26:2-111) is amended to read as follows:

C.26:2-111 Newborn Screening Program; fees.

2. The Newborn Screening Program in the Department of Health shall screen all infants born in this State based on the list of disorders that is recommended by the Newborn Screening Advisory Review Committee and approved by the Commissioner of Health, with consideration of the Recommended Uniform Screening Panel of the United States Secretary of Health and Human Services. The Commissioner of Health may issue regulations to assure that newborns are screened in a manner approved by the commissioner.

The Department of Health shall charge a reasonable fee for the screening, follow-up, treatment, and education performed pursuant to this act. The amount of the fee shall be adjusted by the commissioner as necessary to support the screening, follow-up, and treatment of newborn infants, and the education of physicians, hospital staffs, nurses, and the public as required by this act. The procedures for collecting the fee shall be determined by the commissioner. The commissioner shall apply all revenues collected from the fees to the screening, follow-up, education, and treatment procedures performed pursuant to this act. The fee shall be used to support the program, including, but not limited to, ongoing infrastructure upgrades, including providing electronic access to physicians to obtain screening results, and follow-up recommendations.

Based on the recommendations of the Newborn Screening Advisory Review Committee established pursuant to section 2 of P.L.2019, c.296 (C.26:2-110a), the commissioner may also require the screening of newborn infants for other disorders if reliable and efficient screening techniques are available. If the commissioner determines that an additional test shall be required, the commissioner, at least 60 days prior to requiring the test, shall so advise the President of the Senate and the Speaker of the General Assembly.

The commissioner shall provide laboratory services and a follow-up program on positive screen cases in order that measures may be taken to prevent death or intellectual or other permanent disabilities. The program shall provide timely information and recommendations for referral to specialist treatment centers for newborn infants who screen positive for disorders pursuant to this section.

The commissioner shall collect screening information on newborn infants in a standardized manner and develop a system for quality assurance which includes the periodic assessment of indicators that are measurable, functional, and appropriate to the conditions for which newborn infants are screened pursuant to this section. The commissioner shall have the authority to use the information collected to provide follow-up to newborn infants with screened positive diagnoses to provide information and recommendations for referral. Information on newborn infants compiled pursuant to this section shall be used by the department and agencies designated by the commissioner for the purposes of carrying out this act, but otherwise the information shall be confidential and not divulged or made public so as to disclose the identity of any person to which it relates, except as provided by law.

The department shall provide education or training on the Newborn Screening Program to physicians, hospital staffs, nurses, and the public concerning newborn screening.

The provisions of this section shall not apply if the parents of a newborn infant provide written notice to the hospital or birthing facility where the newborn infant was delivered, in a manner designated by the commissioner, that they object to the screening on the grounds that it would conflict with their religious tenets or practices.

4. The Department of Health may adopt, pursuant to the "Administrative Procedure Act," P.L.1968 c.410 (C.52:14B-1 et seq.), rules and regulations necessary to implement the provisions of this act.

5. This act shall take effect on the 180th day following enactment, except that the Commissioner of Health may take such anticipatory action in advance as shall be necessary for its implementation.

Approved January 13, 2020.