THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE BILL

No. 1478 Session of 2015

INTRODUCED BY ROZZI, O'BRIEN, HARKINS, YOUNGBLOOD, CALTAGIRONE, THOMAS, BISHOP, KINSEY, V. BROWN, PASHINSKI, McNEILL, MILLARD, MURT, M. DALEY, A. HARRIS, FARINA, D. COSTA AND COHEN, AUGUST 10, 2015

REFERRED TO COMMITTEE ON HEALTH, AUGUST 10, 2015

AN ACT

- 1 Establishing the Infant Vision Information, Education and
- 2 Wellness Program; and providing for powers and duties of the
- 3 Department of Health.
- 4 The General Assembly of the Commonwealth of Pennsylvania
- 5 hereby enacts as follows:
- 6 Section 1. Short title.
- 7 This act shall be known and may be cited as the Infant Vision
- 8 Information, Education and Wellness Act.
- 9 Section 2. Legislative findings and purpose.
- 10 (a) Findings.--The General Assembly finds as follows:
- 11 (1) Early detection of vision-threatening and
- 12 potentially life-threatening vision abnormalities is vital
- for early treatment of ocular diseases that occur frequently
- in newborns and infants.
- 15 (2) Emphasis on early detection of vision abnormalities,
- 16 including cataracts, glaucoma, leukocoria, retinoblastoma,
- 17 retinal abnormalities, systemic diseases with ocular

- manifestations and high refractive errors, can help prevent long-term disability and developmental delays in children.
 - (3) Children with abnormal ocular diseases who receive screening during the neonatal and infant period must be referred to an ophthalmologist or optometrist for follow-up consultation and treatment.
 - (4) The American Academy of Pediatrics currently recommends red reflex assessment as a component of the vision evaluation during the neonatal period and during all subsequent routine health visits.
 - (5) The red reflex assessment is conducted by a pediatrician or other primary care provider using an ophthalmoscope during the neonatal period after birth, at the age of six weeks and during routine health visits.
 - (b) Purpose. -- The purposes of this act are to provide:
- Infant vision screening for all newborns born in a 16 17 hospital or within 30 days of the date of birth for those 18 newborns born outside a hospital to enable these infants and 19 their families to obtain needed comprehensive evaluation, 20 treatment and intervention services at the earliest 21 opportunity and to thus prevent or mitigate the developmental 22 delays and excessive costs associated with late identification of vision abnormalities. 23
 - (2) The Department of Health with the information necessary to effectively plan, establish, administer and evaluate this comprehensive program of appropriate services for newborns, infants and children who have vision abnormalities.
- 29 Section 3. Definitions.
- The following words and phrases when used in this act shall

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- 1 have the meanings given to them in this section unless the
- 2 context clearly indicates otherwise:
- 3 "Birth admission." The time after birth that the newborn
- 4 remains in the hospital or birth center prior to discharge.
- 5 "Birth center." An entity licensed as a birth center under
- 6 the act of July 19, 1979 (P.L.130, No.48), known as the Health
- 7 Care Facilities Act.
- 8 "Child." An individual who is under 21 years of age.
- 9 "Committee." The Department of Health's Newborn Vision
- 10 Screening Advisory Committee.
- "Department." The Department of Health of the Commonwealth.
- "Early intervention." The Statewide system of coordinated,
- 13 multidisciplinary, interagency programs in existence on the
- 14 effective date of this act maintained by the Department of
- 15 Education, the Department of Health and the Department of Human
- 16 Services to provide appropriate services to all eligible
- 17 infants, children and their families under the act of December
- 18 19, 1990 (P.L.1372, No.212), known as the Early Intervention
- 19 Services System Act.
- 20 "Health care facility." A hospital providing clinically
- 21 related health services for obstetrical and newborn care, or a
- 22 birth center. The term includes a hospital providing clinically
- 23 related health services for obstetrical and newborn care, or a
- 24 birth center operated by an agency, the State or local
- 25 government. The term does not include an office used primarily
- 26 for private or group practice by health care practitioners if no
- 27 reviewable clinically related health services are offered.
- "Infant." A child 30 days of age up to 24 months of age.
- 29 "Newborn." A child up to and including 29 days of age.
- 30 "Parent." A natural parent, stepparent, adoptive parent,

- 1 legal guardian or legal custodian of a child.
- 2 "Program." The Infant Vision Information, Education and
- 3 Wellness Program.
- 4 "Secretary." The Secretary of Health of the Commonwealth.
- 5 Section 4. The Newborn Vision Screening Advisory Committee.
- 6 (a) Membership. -- The secretary shall appoint a six-member
- 7 Newborn Vision Screening Advisory Committee within the
- 8 department. The committee shall:
- 9 (1) Advise and make recommendations on issues relating
- 10 to the following:
- 11 (i) Program regulation and administration.
- 12 (ii) Diagnostic testing.
- 13 (iii) Technical support.
- 14 (iv) Follow-up.
- 15 (2) Be comprised of members with experience with infant
- eye pathology, pediatric ophthalmology, optometry and common
- vision screening and assessment tests.
- 18 (b) Compensation.--Members shall serve without compensation
- 19 but may be reimbursed for necessary travel and other expenses in
- 20 accordance with applicable law and regulations.
- 21 (c) Protocol.--On or before June 30, 2016, the department
- 22 shall adopt the protocol developed by the American Academy of
- 23 Pediatrics to optimally detect the presence of treatable causes
- 24 of blindness in infants by two months of age. If a protocol is
- 25 not developed on or before June 30, 2016, the department, in
- 26 consultation with the committee, shall establish a protocol to
- 27 optimally detect the presence of treatable causes of blindness
- 28 in infants by two months of age on or before January 1, 2017.
- 29 Section 5. Newborn vision screening education and assessment.
- 30 (a) Establishment. -- The department shall establish the

- 1 Infant Vision Information, Education and Wellness Program,
- 2 consisting of the following components:
- 3 (1) A system to screen each newborn in this Commonwealth
- 4 for vision abnormalities before leaving a hospital.
- 5 (2) A system to screen each newborn who is not born in a
- 6 hospital within the first 30 days of life.
- 7 (3) A system to provide information and instruction to
- 8 the parents of each newborn and infant on the merits of
- 9 having vision screening performed and receiving follow-up
- 10 care.
- 11 (b) Program administration. -- The department shall, in
- 12 cooperation with the committee, provide technical support,
- 13 including ophthalmological, optometric and administrative
- 14 technical support, to the health care facilities and individuals
- 15 implementing the requirements of subsection (a).
- 16 (c) Refusal of test. -- Screening shall not be required if a
- 17 parent of the newborn or infant objects to the screening for any
- 18 reason. The refusal must be documented in writing, made a part
- 19 of the medical record of the newborn or infant and reported to
- 20 the department in a manner prescribed by the department.
- 21 (d) Implementation.--The program shall be implemented as
- 22 follows:
- 23 (1) By July 1, 2017, newborn and infant vision screening
- shall be conducted on each live birth in health care
- facilities in this Commonwealth during birth admissions using
- 26 procedures recommended by the department's advisory
- committee, except as provided in subsection (c). If a newborn
- is born in a location other than a hospital, the parents must
- 29 be instructed on the merits of having the vision screening
- 30 performed and given information to assist the parents in

- 1 having the screening performed within 30 days of the
- 2 newborn's birth. The department shall determine the
- 3 appropriate screening venue for a newborn born outside a
- 4 hospital.
- 5 (2) If the number of newborns and infants receiving
- 6 vision screening does not equal at least 85% of the total
- 7 number of live births in this Commonwealth on July 1, 2017,
- 8 as shown in the most recent data collected by the department
- 9 or falls below 85% annually after July 1, 2017, the
- department in consultation with the advisory committee shall
- immediately promulgate regulations to implement a State-
- 12 administered vision screening program.
- 13 (3) By July 1, 2016, each health care facility in this
- 14 Commonwealth shall provide information and instruct the
- parents of newborns and infants concerning the importance of
- screening the vision of newborns and infants and of receiving
- 17 follow-up care. The information shall be as follows:
- 18 (i) An informational pamphlet developed and supplied
- by the department shall explain in lay terms all of the
- 20 following:
- 21 (A) The importance and process of vision
- 22 screening.
- 23 (B) The likelihood of a newborn or infant having
- vision abnormalities.
- 25 (C) Follow-up procedures and available early
- intervention services.
- 27 (D) A description of the normal vision
- developmental process in children.
- 29 (ii) The information under subparagraph (i) shall
- not preclude the health care facility from providing

1 additional material.

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- 2 (iii) The information may not be considered a substitute for the vision screening.
 - (4) By July 1, 2016, every hospital in this Commonwealth shall report to the department, in a manner prescribed by the department, the number of newborns and infants screened and the results of the screening. The department, based on the information, shall report to the General Assembly by January 1, 2017, and every January 1 thereafter, the following:
 - (i) The number of hospitals conducting vision screenings during birth admissions.
 - (ii) The number of live births in hospitals.
- 13 (iii) The number of newborns screened during birth admissions.
- 15 (iv) The number of live births in a location other 16 than a hospital.
 - (v) The number of newborns born in a location other than a hospital who were screened within 30 days of the date of birth.
 - (vi) The number of newborns born in a hospital who passed and the number who did not pass the birth admission screening, if administered.
 - (vii) The number of newborns born in a location other than a hospital who passed and the number who did not pass a screening within 30 days of the date of birth, if administered.
- 27 (viii) The number of infants who returned for follow-up rescreening.
- 29 (ix) The number of infants who passed the follow-up 30 rescreening.

- 1 (x) The number of infants recommended for
- 2 monitoring, intervention and follow-up care.
- 3 Section 6. Reporting and referral.
- 4 (a) Duties. -- The department shall implement a reporting and
- 5 referral system that links vision screening, if necessary, with
- 6 optometric and ophthalmologist services and other early
- 7 intervention services. The Commonwealth may do all the
- 8 following:
- 9 (1) Identify 100% of newborns and infants with vision
- abnormalities within 30 days of the date of birth.
- 11 (2) Provide timely assessment if indicated.
- 12 (3) Provide appropriate referral for treatment and
- intervention before the age of six months.
- 14 (b) Program administration. -- The department shall, in
- 15 consultation with the committee, provide administrative
- 16 technical support to the facilities implementing the reporting
- 17 and early intervention referral system under this section.
- 18 (c) Implementation. -- The department, in consultation with
- 19 the committee, shall issue temporary guidelines by July 1, 2016,
- 20 implementing a reporting and early intervention referral system
- 21 for newborns, infants and children who have been recommended for
- 22 further assessment. The temporary guidelines shall expire on
- 23 June 30, 2017, or upon promulgation of regulations under section
- 24 8, whichever occurs first.
- 25 Section 7. Confidentiality of records.
- 26 (a) Limitations.--A person, employee or agent of a person
- 27 who obtains information under this act may not disclose the
- 28 information except to the parent of the infant or child or to
- 29 the department for statistical recordkeeping or for appropriate
- 30 treatment referral and early intervention services.

- 1 (b) Confidentiality.--
- 2 (1) Data obtained directly from the medical records of a
- 3 patient shall be considered confidential and shall be for the
- 4 confidential use of the department in maintaining the
- 5 tracking system and in providing appropriate services. The
- 6 information shall be privileged and may not be divulged or
- 7 made public in any manner that discloses the identity of the
- 8 patient. Information considered confidential under this
- 9 paragraph shall be exempt from access under the act of
- 10 February 14, 2008 (P.L.6, No.3), known as the Right-to-Know
- 11 Law.
- 12 (2) Anonymous statistical information collected under
- the tracking system shall be considered a public record under
- 14 the Right-to-Know Law.
- 15 (c) Good faith. -- A person who acts in good faith in
- 16 complying with this section by reporting newborn and infant
- 17 vision screening results to the department may not be held
- 18 civilly or criminally liable for furnishing the information
- 19 required by this act.
- 20 Section 8. Regulations.
- 21 The department shall promulgate regulations to implement the
- 22 provisions of this act.
- 23 Section 9. Effective date.
- 24 This act shall take effect in 90 days.