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LRB094 06314 LJB 41500 a

1 AMENDMENT TO HOUSE BILL 480

2 AMENDMENT NO. _____. Amend House Bill 480 by replacing the
3 title with the following:

4 "AN ACT concerning public health, which may be referred to
5 as Adamin and Ryan's Law."; and

6 by replacing everything after the enacting clause with the
7 following:

8 "Section 1. Short title. This Act may be cited as the
9 Newborn Eye Pathology Screening Act.

10 Section 5. Policy and legislative findings.

11 (a) It is the policy of the State of Illinois to make every
12 effort to detect pediatric congenital ocular abnormalities
13 that lead to premature death, blindness, or vision impairment
14 unless treated soon after birth.

15 (b) The General Assembly finds and declares the following:

16 (1) Treatable congenital ocular diseases occur
17 frequently and require increased early detection efforts.

18 (2) Early detection significantly enhances the ability
19 to prevent serious damage from congenital abnormalities of
20 the eye which, left undetected and untreated, may result in
21 blinding or life-threatening diseases, or both. Examples
22 of such disorders include retinoblastoma, congenital
23 cataracts, and persistent hyperplastic primary vitreous.

1 Other congenital anomalies, including colobomas, vascular
2 retinal anomalies, and congenital retinal folds, can be
3 treated by patching the good eye to prevent dense amblyopia
4 if detected early.

5 (3) Retinoblastoma is a childhood cancer arising in
6 immature retinal cells inside the eye and accounts for
7 approximately 13% of all cancers in infants. Most children
8 are diagnosed before 2 1/2 years of age. When
9 retinoblastoma affects both eyes, the average age of
10 diagnosis is 12 months.

11 (4) Increased emphasis on optimal examination methods,
12 such as dilation of the eye with eye drops, may facilitate
13 detection of the abnormal disease process inside the eye of
14 the newborn. An abnormal screen will facilitate timely
15 referral to an appropriately licensed health care provider
16 acting within his or her scope of practice for diagnosis
17 and to an ophthalmologist for treatment.

18 (5) Early detection and referral of an abnormal red
19 reflex pupillary screen would allow early diagnosis of
20 congenital cataract or retinoblastoma which, if recognized
21 and treated as soon as possible after birth, could cause
22 little long-term disability.

23 (6) Early diagnosis and intervention can reduce the
24 number of visually impaired citizens and reduce the amount
25 of public expenditures for health care, special education,
26 and related services.

27 Section 10. Newborn Eye Pathology Screening Advisory
28 Committee.

29 (a) By January 1, 2006, the Department of Human Services
30 shall organize a Newborn Eye Pathology Screening Advisory
31 Committee and appoint members of the Advisory Committee,
32 including, but not limited to, the following:

33 (1) Two ophthalmologists with backgrounds in or

1 knowledge of providing services to infants with
2 retinoblastoma, one from the Chicago metropolitan area and
3 one from the southern counties of Illinois.

4 (2) A pediatric ophthalmologist who sees general
5 pediatric patients and is a designee of the American
6 Association for Pediatric Ophthalmology and Strabismus.

7 (3) An academic pediatrician with a background in or
8 knowledge of infant eye pathology screening.

9 (4) Two parents representing families with child
10 blindness or other ocular abnormalities affecting vision,
11 one from the Chicago metropolitan area and one from the
12 southern counties of Illinois.

13 (5) A community pediatrician with a background in or
14 experience with the routine instillation of dilating eye
15 drops as part of the red reflex screening.

16 (6) A nurse with a background in or knowledge of the
17 current Department's program for instillation of eye drops
18 to prevent conjunctivitis.

19 (7) A retinal specialist with research experience in
20 detecting the signs of treatable congenital eye disease.

21 (8) An optometrist with a background in or experience
22 with pupil dilation in infants and red reflex screening for
23 intraocular pathology.

24 (b) The Advisory Committee members shall serve without
25 compensation, but shall be reimbursed for necessary travel
26 expenses incurred in the performance of their duties.

27 (c) The duties of the Advisory Committee shall be to do all
28 of the following:

29 (1) Develop and conduct training for hospitals
30 implementing newborn hearing screening.

31 (2) Develop a referral system for early intervention
32 services for those infants diagnosed with a congenital
33 abnormality of the eye.

34 (3) Develop educational and informational materials

1 for hospital personnel, health care professionals, and
2 parents on appropriate follow-up procedures for infants
3 diagnosed with a congenital abnormality of the eye.

4 (4) Monitor any reports made available to the State
5 with respect to the eye pathology screening status of all
6 newborns.

7 (5) Review administrative rules and make
8 recommendations to the Department regarding the rules.

9 Section 20. Protocol; required screening.

10 (a) By January 1, 2006, the Department shall adopt the
11 protocol developed by the American Academy of Pediatrics to
12 optimally detect the presence of treatable causes of blindness
13 in infants by 2 months of age.

14 (b) After January 1, 2006, all hospitals shall conduct eye
15 screenings of all newborns prior to discharge.

16 (c) Any screening examination recommended pursuant to
17 subsection (a) of this Section or required pursuant to
18 subsection (b) of this Section shall not be conducted on a
19 newborn if a parent or guardian of the newborn objects to the
20 examination on the grounds that the examination conflicts with
21 the religious beliefs or practices of the parent or guardian. A
22 written statement of the objection shall be presented to the
23 physician or other person whose duty it is to administer and
24 report the screening under the provisions of this Act.

25 (d) Nothing in this Section shall be construed to supersede
26 the clinical judgment of the licensed health care provider.

27 Section 25. Department of Public Health.

28 (a) Hospitals shall report information about each child
29 with a positive eye screening result to the Illinois Department
30 of Public Health.

31 (b) The Illinois Department of Public Health shall maintain
32 a registry of cases of positive eye screening results,

1 including information needed for the purpose of follow-up
2 service.

3 Section 30. Rules. The Department of Human Services shall
4 adopt rules necessary to implement this Act.

5 Section 99. Effective date. This Act takes effect July 1,
6 2005.".