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IN SENATE

April 20, 2016

Introduced by Sen. SANDERS -- read twice and ordered printed, and when printed to be committed to the Committee on Health

AN ACT to amend the public health law, in relation to establishing the infant vision information, education and wellness program

THE PEOPLE OF THE STATE OF NEW YORK, REPRESENTED IN SENATE AND ASSEMBLY, DO ENACT AS FOLLOWS:

Section 1. Short title. This act shall be known and may be cited as the "Infant Vision Information, Education and Wellness Act".

S 2. The public health law is amended by adding a new title II-B to article 25 to read as follows:

TITLE II-B

6 INFANT VISION INFORMATION, EDUCATION AND WELLNESS PROGRAM 7 SECTION 2560. DEFINITIONS.

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- 2561. NEWBORN VISION SCREENING ADVISORY COMMITTEE.
- 2562. NEWBORN VISION SCREENING EDUCATION AND ASSESSMENT.
- 2563. REPORTING AND REFERRAL.

2564. CONFIDENTIALITY OF RECORDS.

2565. REGULATORY AUTHORITY.

13 S 2560. DEFINITIONS. THE FOLLOWING WORDS AND PHRASES, AS USED IN THIS 14 SECTION SHALL HAVE THE FOLLOWING MEANINGS UNLESS THE CONTEXT CLEARLY 15 INDICATES OTHERWISE:

16 1. "BIRTH ADMISSION" SHALL MEAN THE TIME AFTER BIRTH THAT A NEWBORN 17 REMAINS IN A HOSPITAL OR BIRTH CENTER PRIOR TO DISCHARGE.

18 2. "CHILD" SHALL MEAN AN INDIVIDUAL WHO IS UNDER TWENTY-ONE YEARS OF 19 AGE.

20 3. "COMMITTEE" SHALL MEAN THE DEPARTMENT OF HEALTH'S NEWBORN VISION 21 SCREENING ADVISORY COMMITTEE.

4. "HEALTH CARE FACILITY" SHALL MEAN A HOSPITAL PROVIDING CLINICALLY
RELATED HEALTH SERVICES FOR OBSTETRICAL AND NEWBORN CARE, OR A BIRTH
CENTER. THE TERM INCLUDES A HOSPITAL PROVIDING CLINICALLY RELATED HEALTH
SERVICES FOR OBSTETRICAL AND NEWBORN CARE, OR A BIRTH CENTER OPERATED BY
AN AGENCY, THE STATE OR LOCAL GOVERNMENT. THE TERM DOES NOT INCLUDE AN
OFFICE USED PRIMARILY FOR PRIVATE OR GROUP PRACTICE BY HEALTH CARE PRAC-

EXPLANATION--Matter in ITALICS (underscored) is new; matter in brackets
[] is old law to be omitted.

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TITIONERS IF NO REVIEWABLE CLINICALLY RELATED HEALTH SERVICES ARE 1 2 OFFERED. 3 5. "INFANT" SHALL MEAN A CHILD THIRTY DAYS OF AGE UP TO TWENTY-FOUR 4 MONTHS OF AGE. 5 6. "NEWBORN" SHALL MEAN A CHILD UP TO AND INCLUDING TWENTY-NINE DAYS 6 OF AGE. 7 7. "PARENT" SHALL MEAN A NATURAL PARENT, STEPPARENT, ADOPTIVE PARENT, 8 LEGAL GUARDIAN OR LEGAL CUSTODIAN OF A CHILD. 9 8. "PROGRAM" SHALL MEAN THE INFANT VISION INFORMATION, EDUCATION AND 10 WELLNESS PROGRAM. 11 S 2561. NEWBORN VISION SCREENING ADVISORY COMMITTEE. 1. MEMBERSHIP. 12 THE COMMISSIONER SHALL APPOINT A SIX-MEMBER NEWBORN VISION SCREENING ADVISORY COMMITTEE WITHIN THE DEPARTMENT. THE COMMITTEE SHALL: 13 14 (A) ADVISE AND MAKE RECOMMENDATIONS ON ISSUES RELATING TO THE FOLLOW-15 ING: 16 (I) PROGRAM REGULATION AND ADMINISTRATION; 17 (II) DIAGNOSTIC TESTING; 18 (III) TECHNICAL SUPPORT; 19 (IV) FOLLOW-UP. 20 (B) BE COMPRISED OF MEMBERS WITH EXPERIENCE WITH INFANT EYE PATHOLOGY, 21 PEDIATRIC OPHTHALMOLOGY, OPTOMETRY AND COMMON VISION SCREENING AND 22 ASSESSMENT TESTS. 23 2. COMPENSATION. MEMBERS SHALL SERVE WITHOUT COMPENSATION BUT MAY BE 24 REIMBURSED FOR NECESSARY TRAVEL AND OTHER EXPENSES IN ACCORDANCE WITH 25 APPLICABLE LAW AND REGULATIONS. 26 3. PROTOCOL. ON OR BEFORE JUNE THIRTIETH, TWO THOUSAND SEVENTEEN, THE DEPARTMENT SHALL ADOPT THE PROTOCOL DEVELOPED BY THE AMERICAN ACADEMY OF 27 28 PEDIATRICS TO OPTIMALLY DETECT THE PRESENCE OF TREATABLE CAUSES OF 29 BLINDNESS IN INFANTS BY TWO MONTHS OF AGE. IF A PROTOCOL IS NOT DEVEL-OPED ON OR BEFORE SUCH DATE, THE DEPARTMENT, IN CONSULTATION WITH THE 30 COMMITTEE, SHALL ESTABLISH A PROTOCOL TO OPTIMALLY DETECT THE PRESENCE 31 32 OF TREATABLE CAUSES OF BLINDNESS IN INFANTS BY TWO MONTHS OF AGE ON OR BEFORE JANUARY FIRST, TWO THOUSAND EIGHTEEN. 33 34 S 2562. NEWBORN VISION SCREENING EDUCATION AND ASSESSMENT. 1. ESTAB-35 LISHMENT. THE DEPARTMENT SHALL ESTABLISH THE INFANT VISION INFORMATION, 36 EDUCATION AND WELLNESS PROGRAM, CONSISTING OF THE FOLLOWING COMPONENTS: 37 (A) A SYSTEM TO SCREEN EACH NEWBORN IN THE STATE FOR VISION ABNOR-38 MALITIES BEFORE LEAVING A HOSPITAL. 39 (B) A SYSTEM TO SCREEN EACH NEWBORN WHO IS NOT BORN IN A HOSPITAL 40 WITHIN THE FIRST THIRTY DAYS OF LIFE. (C) A SYSTEM TO PROVIDE INFORMATION AND INSTRUCTION TO THE PARENTS OF 41 42 EACH NEWBORN AND INFANT ON THE MERITS OF HAVING VISION SCREENING 43 PERFORMED AND RECEIVING FOLLOW-UP CARE. 44 PROGRAM ADMINISTRATION. THE DEPARTMENT SHALL, IN COOPERATION WITH 2. 45 THE COMMITTEE, PROVIDE TECHNICAL SUPPORT, INCLUDING OPHTHALMOLOGICAL, OPTOMETRIC AND ADMINISTRATIVE TECHNICAL SUPPORT, TO THE HEALTH CARE 46 47 FACILITIES AND INDIVIDUALS IMPLEMENTING THE REQUIREMENTS OF SUBDIVISION 48 ONE OF THIS SECTION. 49 3. REFUSAL OF TEST. SCREENING SHALL NOT BE REQUIRED IF A PARENT OF THE 50 NEWBORN OR INFANT OBJECTS TO THE SCREENING FOR ANY REASON. THE REFUSAL 51 MUST BE DOCUMENTED IN WRITING, MADE A PART OF THE MEDICAL RECORD OF THE NEWBORN OR INFANT AND REPORTED TO THE DEPARTMENT IN A MANNER PRESCRIBED 52 53 BY THE DEPARTMENT. 54 4. IMPLEMENTATION. THE PROGRAM SHALL BE IMPLEMENTED AS FOLLOWS: 55 (A) BY JULY FIRST, TWO THOUSAND EIGHTEEN, NEWBORN AND INFANT VISION 56 SCREENING SHALL BE CONDUCTED ON EACH LIVE BIRTH IN HEALTH CARE FACILI-

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9 (B) IF THE NUMBER OF NEWBORNS AND INFANTS RECEIVING VISION SCREENING 10 DOES NOT EQUAL AT LEAST EIGHTY-FIVE PERCENT OF THE TOTAL NUMBER OF LIVE BIRTHS IN THE STATE ON JULY FIRST, TWO THOUSAND EIGHTEEN, AS SHOWN IN 11 THE MOST RECENT DATA COLLECTED BY THE DEPARTMENT OR FALLS BELOW EIGHTY-12 FIVE PERCENT ANNUALLY AFTER JULY FIRST, TWO THOUSAND EIGHTEEN, THE 13 14 DEPARTMENT IN CONSULTATION WITH THE ADVISORY COMMITTEE SHALL IMMEDIATELY 15 PROMULGATE REGULATIONS TO IMPLEMENT A STATE-ADMINISTERED VISION SCREEN-16 ING PROGRAM.

17 BY JULY FIRST, TWO THOUSAND SEVENTEEN, EACH HEALTH CARE FACILITY (C) 18 IN THE STATE SHALL PROVIDE INFORMATION AND INSTRUCT THE PARENTS OF 19 NEWBORNS AND INFANTS CONCERNING THE IMPORTANCE OF SCREENING THE VISION 20 OF NEWBORNS AND INFANTS AND OF RECEIVING FOLLOW-UP CARE. THE INFORMATION 21 SHALL BE AS FOLLOWS:

(I) AN INFORMATIONAL PAMPHLET DEVELOPED AND SUPPLIED BY THE DEPARTMENT 22 23 SHALL EXPLAIN IN LAY TERMS ALL OF THE FOLLOWING:

(A) THE IMPORTANCE AND PROCESS OF VISION SCREENING.

(B) THE LIKELIHOOD OF A NEWBORN OR INFANT HAVING VISION ABNORMALITIES.

26 (C) FOLLOW-UP PROCEDURES AND AVAILABLE EARLY INTERVENTION SERVICES.

27 (D) A DESCRIPTION OF THE NORMAL VISION DEVELOPMENTAL PROCESS IN CHIL-28 DREN.

29 (II) THE INFORMATION UNDER SUBPARAGRAPH (I) OF THIS PARAGRAPH SHALL 30 NOT PRECLUDE THE HEALTH CARE FACILITY FROM PROVIDING ADDITIONAL MATERI-31 AL.

32 INFORMATION MAY NOT BE CONSIDERED A SUBSTITUTE FOR THE (III) THE 33 VISION SCREENING.

34 (D) BY JULY FIRST, TWO THOUSAND SEVENTEEN, EVERY HOSPITAL IN THE STATE SHALL REPORT TO THE DEPARTMENT, IN A MANNER PRESCRIBED BY THE DEPART-35 MENT, THE NUMBER OF NEWBORNS AND INFANTS SCREENED AND THE RESULTS OF THE 36 37 SCREENING. THE DEPARTMENT, BASED ON THE INFORMATION, SHALL REPORT TO THE 38 LEGISLATURE BY JANUARY FIRST, TWO THOUSAND EIGHTEEN, AND EVERY JANUARY FIRST THEREAFTER, THE FOLLOWING: 39

40 (I) THE NUMBER OF HOSPITALS CONDUCTING VISION SCREENINGS DURING BIRTH 41 ADMISSIONS.

(II) THE NUMBER OF LIVE BIRTHS IN HOSPITALS. 42

43 (III) THE NUMBER OF NEWBORNS SCREENED DURING BIRTH ADMISSIONS.

44 (IV) THE NUMBER OF LIVE BIRTHS IN A LOCATION OTHER THAN A HOSPITAL.

45 (V) THE NUMBER OF NEWBORNS BORN IN A LOCATION OTHER THAN A HOSPITAL WHO WERE SCREENED WITHIN THIRTY DAYS OF THE DATE OF BIRTH. 46

47 (VI) THE NUMBER OF NEWBORNS BORN IN A HOSPITAL WHO PASSED AND THE 48 NUMBER WHO DID NOT PASS THE BIRTH ADMISSION SCREENING, IF ADMINISTERED.

49 (VII) THE NUMBER OF NEWBORNS BORN IN A LOCATION OTHER THAN A HOSPITAL 50 WHO PASSED AND THE NUMBER WHO DID NOT PASS A SCREENING WITHIN THIRTY 51 DAYS OF THE DATE OF BIRTH, IF ADMINISTERED.

(VIII) THE NUMBER OF INFANTS WHO RETURNED FOR FOLLOW-UP RESCREENING. 52

53 (IX) THE NUMBER OF INFANTS WHO PASSED THE FOLLOW-UP RESCREENING.

54 (X) THE NUMBER OF INFANTS RECOMMENDED FOR MONITORING, INTERVENTION AND 55 FOLLOW UP CARE.

2563. REPORTING AND REFERRAL. 1. DUTIES. THE DEPARTMENT SHALL 1 S 2 IMPLEMENT A REPORTING AND REFERRAL SYSTEM THAT LINKS VISION SCREENING, 3 IF NECESSARY, WITH OPTOMETRIC AND OPTHALMOLOGIST SERVICES AND OTHER EARLY INTERVENTION SERVICES. THE STATE MAY DO ALL THE FOLLOWING: 4

5 IDENTIFY ONE HUNDRED PERCENT OF NEWBORNS AND INFANTS WITH VISION (A) 6 ABNORMALITIES WITHIN THIRTY DAYS OF THE DATE OF BIRTH. 7

(B) PROVIDE TIMELY ASSESSMENT IF INDICATED.

8 (C) PROVIDE APPROPRIATE REFERRAL FOR TREATMENT AND INTERVENTION BEFORE 9 THE AGE OF SIX MONTHS.

10 2. PROGRAM ADMINISTRATION. THE DEPARTMENT SHALL, IN CONSULTATION WITH THE COMMITTEE, PROVIDE ADMINISTRATIVE TECHNICAL SUPPORT TO THE FACILI-11 TIES IMPLEMENTING THE REPORTING AND EARLY INTERVENTION REFERRAL SYSTEM 12 13 UNDER THIS SECTION.

14 3. IMPLEMENTATION. THE DEPARTMENT, IN CONSULTATION WITH THE COMMITTEE, SHALL ISSUE TEMPORARY GUIDELINES BY JULY FIRST, TWO THOUSAND SEVENTEEN, 15 16 IMPLEMENTING A REPORTING AND EARLY INTERVENTION REFERRAL SYSTEM FOR 17 NEWBORNS, INFANTS AND CHILDREN WHO HAVE BEEN RECOMMENDED FOR FURTHER ASSESSMENT. THE TEMPORARY GUIDELINES SHALL EXPIRE ON JUNE THIRTIETH, TWO 18 19 THOUSAND EIGHTEEN.

20 S 2564. CONFIDENTIALITY OF RECORDS. 1. LIMITATIONS. A PERSON, EMPLOY-21 EE OR AGENT OF A PERSON WHO OBTAINS INFORMATION UNDER THIS ACT MAY NOT DISCLOSE THE INFORMATION EXCEPT TO THE PARENT OF THE INFANT OR CHILD OR 22 23 TO THE DEPARTMENT FOR STATISTICAL RECORDKEEPING OR FOR APPROPRIATE 24 TREATMENT REFERRAL AND EARLY INTERVENTION SERVICES.

25 2. CONFIDENTIALITY. DATA OBTAINED DIRECTLY FROM THE MEDICAL RECORDS OF 26 PATIENT SHALL BE CONSIDERED CONFIDENTIAL AND SHALL BE FOR THE CONFI-А 27 DENTIAL USE OF THE DEPARTMENT IN MAINTAINING THE TRACKING SYSTEM AND IN PROVIDING APPROPRIATE SERVICES. THE INFORMATION SHALL BE PRIVILEGED AND 28 29 MAY NOT BE DIVULGED OR MADE PUBLIC IN ANY MANNER THAT DISCLOSES THE IDENTITY OF THE PATIENT. 30

A PERSON WHO ACTS IN GOOD FAITH IN COMPLYING WITH THIS SECTION BY 31 32 REPORTING NEWBORN AND INFANT VISION SCREENING RESULTS TO THE DEPARTMENT 33 MAY NOT BE HELD CIVILLY OR CRIMINALLY LIABLE FOR FURNISHING THE INFORMA-34 TION REQUIRED BY THIS TITLE.

35 2565. REGULATORY AUTHORITY. THE DEPARTMENT SHALL PROMULGATE SUCH S RULES AND REGULATIONS AS MAY BE NECESSARY TO IMPLEMENT THE PROVISIONS OF 36 37 THIS TITLE.

S 3. This act shall take effect on the ninetieth day after it shall 38 39 have become a law; provided, however, that effective immediately, the addition, amendment and/or repeal of any rule or regulation necessary 40 for the implementation of this act on its effective date is authorized 41 and directed to be made and completed on or before such date. 42