

BY: Health and Government Operations Committee

AMENDMENTS TO HOUSE BILL NO. 1315  
(First Reading File Bill)

AMENDMENT NO. 1

On page 1, in line 4, after the first “and” insert “certain”; and in line 8, after “investigations;” insert “requiring the Department to obtain the informed consent of parents or guardians with or without a birth defect before obtaining certain medical records or including the child in certain research;”.

AMENDMENT NO. 2

On page 2, in line 19, after “representatives” insert “, EPIDEMIOLOGISTS, PARENTS OF CHILDREN WITH BIRTH DEFECTS,”; in line 27, after “RECORDS” insert “:

- (I) OF THE CHILD THROUGH THE SECOND YEAR OF LIFE; AND
- (II) OF THE MOTHER RELATING TO THE PREGNANCY WITH THIS CHILD”;

in line 28, after “TESTS” insert “RELATING TO THE BIRTH DEFECT”; and in line 29, after “INFORMATION” insert “RELATING TO THE BIRTH DEFECT”.

AMENDMENT NO. 3

On page 3, strike in their entirety lines 14 through 17, inclusive, and substitute:

“(II) THE DEPARTMENT SHALL OBTAIN THE INFORMED CONSENT OF THE PARENT OR GUARDIAN OF A CHILD WITH OR WITHOUT A BIRTH DEFECT BEFORE:

- 1. OBTAINING THE MEDICAL RECORDS OF THE CHILD FOR ANY RESEARCH REQUIRING APPROVAL BY AN INSTITUTIONAL REVIEW BOARD;  
OR

(Over)

2. INCLUDING THE CHILD IN ANY RESEARCH REQUIRING APPROVAL BY AN INSTITUTIONAL REVIEW BOARD.”;

after line 24, insert:

“(I) THE BIRTH DEFECT;”;

in lines 25, 26, 28, and 30, strike “(I)”, “(II)”, “(III)”, and “(IV)”, respectively, and substitute “(II)”, “(III)”, “(IV)”, and “(V)”, respectively; and in line 30, after “DEPARTMENT’S” insert “INSTITUTIONAL REVIEW BOARD APPROVED”.

On page 4, in line 6, after “SUBJECTS” insert “, INCLUDING OBTAINING APPROPRIATE INSTITUTIONAL REVIEW BOARD APPROVAL AND FOLLOWING THE BOARD’S PROTOCOL”.