

1 AN ACT relating to Down syndrome and spina bifida information.

2 ***Be it enacted by the General Assembly of the Commonwealth of Kentucky:***

3 ➔Section 1. KRS 211.192 is amended to read as follows:

4 (1) For the purposes of this section:

5 (a) "Down syndrome" means a chromosomal condition caused by cell division
6 that results in the presence of an extra whole or partial copy of chromosome
7 21; and

8 (b) "Spina bifida" means a neural tube defect, the most common of which is the
9 open neural tube defect myelomeningocele.

10 (2) A health facility as defined in KRS 216B.015~~[(13)]~~, physician, health care provider,
11 nurse midwife, **licensed certified professional midwife**, or genetic counselor who
12 renders prenatal care, postnatal care, or genetic counseling, upon receipt of a
13 positive test result from a test for Down syndrome or spina bifida, shall provide the
14 expectant or new parent with information provided by the Cabinet for Health and
15 Family Services under subsection (3) of this section.

16 (3) The Cabinet for Health and Family Services shall make available to any person who
17 renders prenatal care, postnatal care, or genetic counseling to parents who receive a
18 prenatal or postnatal diagnosis of Down syndrome or spina bifida and to any person
19 who has received a positive test result from a test for Down syndrome or spina
20 bifida the following:

21 (a) Up-to-date, evidence-based, written information about Down syndrome or
22 spina bifida that has been reviewed by medical experts and Down syndrome or
23 spina bifida organizations and includes information on physical,
24 developmental, educational, and psychosocial outcomes, life expectancy,
25 clinical course, intellectual and functional development, and treatment
26 options; and

27 (b) Contact information regarding support programs and services for expectant

1 and new parents of children with Down syndrome or spina bifida, including
2 information hotlines specific to Down syndrome or spina bifida, resource
3 centers or clearinghouses, national and local Down syndrome or spina bifida
4 organizations such as Down Syndrome of Louisville, Down Syndrome
5 Association of Central Kentucky, Down Syndrome Association of South
6 Central Kentucky, Green River Area Down Syndrome Association, Down
7 Syndrome Association of Greater Cincinnati Serving Northern Kentucky,
8 Council on Developmental Disabilities, the Spina Bifida Association of
9 Kentucky, and other education and support programs.

10 **(4) A health facility as defined in KRS 216B.015, physician, health care provider,**
11 **nurse midwife, licensed certified professional midwife, or genetic counselor who**
12 **renders prenatal care, postnatal care, or genetic counseling shall submit**
13 **documentation of compliance with provisions of this section each year to the**
14 **Cabinet for Health and Family Services. The annual documentation requirement**
15 **shall be a condition of payment or reimbursement by the cabinet for the provision**
16 **of health care services.**