

AN ACT relating to the provision of information relative to spina bifida.

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

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

(1) For the purposes of this section:~~[-]~~

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

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

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

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

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

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

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