# Legislative Analysis

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## PROVISION OF SPINA BIFIDA INFORMATION TO PARENTS

**House Bill 4584 as introduced**
**Sponsor: Rep. Hank Vaupel**
**Committee: Health Policy**
**Complete to 5-12-17**

## SUMMARY:

House Bill 4584 would add a section to the Public Health Code to ensure that expectant or new parents of children with spina bifida are provided with certain information about that condition. (Proposed MCL 333.5822) The bill would take effect 90 days after enactment.

> ***Spina bifida*** refers to a congenital malformation of the bone in the vertebral column that exposes the spinal cord, which is caused by incomplete closing of the embryonic neural tube.

Specifically, if a child receives a prenatal or postnatal test or diagnosis of spina bifida, the health facility or provider must give the child's parents the following information, provided by the Michigan Department of Health and Human Services (MDHHS):

- Up to date, evidence-based written information about spina bifida that has been reviewed by medical experts and spina bifida organizations, including information on physical developmental, educational, and psychological outcomes, life expectancy, clinical course, intellectual and functional development, and treatment options.

- Contact information regarding support programs and services that may be available to expectant and new parents of children with spina bifida, including hotlines specific to spina bifida, resource centers or clearinghouses, and national and local spina bifida organizations.

MDHHS must make available the above information to any person who renders prenatal care, postnatal care, or genetic counseling to parents who receive a prenatal or postnatal diagnosis of spina bifida, and to any person who receives a positive test result from a test for spina bifida. Additionally, the bill would require MDHHS to post links to credible sources of educational materials on spina bifida, such as the National Spina Bifida Association, the Centers for Disease Control and Prevention, and the March of Dimes, on its website.

The following organizations and individuals must provide the above information to the parents: a health care facility or agency licensed under Article 17 of the Public Health Code, or a physician, health care provider, nurse midwife, or genetic counselor that renders prenatal care, postnatal care, or genetic counseling.

## FISCAL IMPACT:

The bill may have modest cost implications for the Department of Health and Human Services (DHHS) to prepare, circulate for expert review, and maintain updated information on spina bifida, contact information for support programs and services, and links on the DHHS website. An estimated cost would $10,000 or less for a first year cost to develop the required materials, and a reduced amount for future year costs to maintain and review materials annually.

DHHS currently supports a statewide Birth Defects Program which includes monitoring the rate of birth defects through a birth defects registry (pursuant to Sec. 5717 and 5721 of the Public Health Code), follow-up activities, and education of individuals, professionals and the public about preventable risk factors through the online Michigan Genetics Resource Center. The program is supported by federal and state funding.

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