

# Legislative Analysis

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## PROVISION OF SPINA BIFIDA INFORMATION TO PARENTS

Phone: (517) 373-8080  
<http://www.house.mi.gov/hfa>

**House Bill 4584 (as reported from committee as H-2)**  
**Sponsor: Rep. Hank Vaupel**  
**Committee: Health Policy**  
**Complete to 6-14-17**

Analysis available at  
<http://www.legislature.mi.gov>

### SUMMARY:

House Bill 4584 would add a section to the Public Health Code to ensure that expectant or new parents of children receiving a positive test for spina bifida are provided with certain information about that condition. 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 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. (MDHHS may make this information available by posting it on its website.)
- 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 and the Centers for Disease Control and Prevention.

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.

Proposed MCL 333.5822

## **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.

## ***POSITIONS:***

The Birth Defects Program Coordinator in the Michigan Department of Health and Human Services testified in support of the bill. (5-17-17)

Representatives of the Spina Bifida Association of Michigan testified in support of the bill. (5-17-17)

The following organizations indicated support for the bill:

- Right to Life of Michigan (5-17-17)
- Michigan Catholic Conference (5-17-17)

The following organizations indicated opposition to the bill:

- Michigan Academy of Family Physicians (5-31-17)
- American Congress of Obstetricians and Gynecologists (5-31-17)

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■ This analysis was prepared by nonpartisan House Fiscal Agency staff for use by House members in their deliberations, and does not constitute an official statement of legislative intent.