

## PROVISION OF SPINA BIFIDA INFORMATION TO PARENTS

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**House Bill 4584 (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>

**BRIEF 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. (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.

**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.

### **THE APPARENT PROBLEM:**

According to committee testimony, spina bifida is often misunderstood by medical professionals and mischaracterized to parents. In spite of mobility and continence issues, as well as other difficulties throughout their lives, individuals with spina bifida typically have normal IQ scores and typical life expectancies. However, during committee testimony, parents recounted the incomplete or misleading information they received, depending on the medical professional handling their case. The bill is intended to ensure that, in the case of a positive spina bifida test, all parents would receive up-to-date, evidence based information about the condition and treatment options, as well as contact information for support programs.

### **THE CONTENT OF THE BILL:**

The bill would require that parents be provided with information about spina bifida upon receipt of their child's positive prenatal or postnatal test for the condition.

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.

### ***ARGUMENTS:***

#### ***For:***

The bill's supporters stated that the requirement that information be provided to parents receiving a positive test result means that parents will be able to make time-sensitive decisions with the best information possible. For instance, for pregnancies diagnosed earlier than 25 weeks gestation, fetal surgeons may be able to operate and close the opening in the fetus' back in utero. This surgery has shown significantly better results than traditional repair after birth.

Some testified, however, that receipt of this important information depended largely on luck. While some doctors delivered the possible diagnosis and referred the parents to applicable specialists to make informed decisions, others stated only that the fetus was "incompatible with life," and still others gave no information at all, preferring not to give incomplete or inaccurate information. Parents testified that they did not want anyone else to face this uncertainty and fear; they believe that continuity in the information provided can address this concern.

***Against:***

According to the Centers for Disease Control, birth defects occur in approximately one out of 33 births in the United States, accounting for nearly 120,000 babies each year.<sup>1</sup> Spina bifida occurs in approximately one out of 2,858 births, accounting for about 1,460 babies each year (based on the latest available data from 2004-2006).<sup>2</sup> Some physicians noted that, while serious, spina bifida is one of many birth defects and accounts for a relatively small number of those defects. Physicians and other health care providers are trained for such situations and are in the best position to inform their patients.

Singling out one of many birth defects (to say nothing of illnesses or conditions which may be contracted by the mother or child during the course of the pregnancy) is unhelpful and unnecessary. More than that, some feel that government intrusion into the doctor-patient relationship is dangerous and that legislation such as this removes medical discretion in favor of political expediency.

Additionally, they argued that standards governing prevention, diagnosis, and management of fetuses and children with spina bifida already exist. The American College of Ob/GYNs has created an internal practice bulletin specifically to cover the practice guidelines for physicians and prenatal care practitioners (most recently reviewed and reaffirmed in 2016). Directives from the legislature about these medical professionals' area of expertise are unnecessary and unhelpful.

***POSITIONS:***

The Birth Defects Program Coordinator in the Michigan Department of Health and Human Services 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)
- Spina Bifida Association of Michigan (5-17-17)

The following organizations indicated opposition to this bill:

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

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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.

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<sup>1</sup> <https://www.cdc.gov/ncbddd/birthdefects/facts.html#references>

<sup>2</sup> <https://www.cdc.gov/ncbddd/birthdefects/data.html>