

☞ **05hr_ab1098_AC-PH_pt01**



Details:

(FORM UPDATED: 07/12/2010)

**WISCONSIN STATE LEGISLATURE ...
PUBLIC HEARING - COMMITTEE RECORDS**

2005-06

(session year)

Assembly

(Assembly, Senate or Joint)

**Committee on ... Public Health
(AC-PH)**

COMMITTEE NOTICES ...

- *Committee Reports ... CR*
- *Executive Sessions ... ES*
- *Public Hearings ... PH*
- *Record of Comm. Proceedings ... RCP*

INFORMATION COLLECTED BY COMMITTEE FOR AND AGAINST PROPOSAL

- *Appointments ... Appt*
- *Clearinghouse Rules ... CRule*
- *Hearing Records ... bills and resolutions*
(*ab* = Assembly Bill) (*ar* = Assembly Resolution) (*afr* = Assembly Joint Resolution)
(*sb* = Senate Bill) (*sr* = Senate Resolution) (*sfr* = Senate Joint Resolution)
- *Miscellaneous ... Misc*

Vote Record Committee on Public Health

Date: 4/19/06

Moved by: Townsend

Seconded by: Freese

AB 1098 SB _____ Clearinghouse Rule _____
 AJR _____ SJR _____ Appointment _____
 AR _____ SR _____ Other _____

A/S Amdt _____
 A/S Amdt _____ to A/S Amdt _____
 A/S Sub Amdt _____
 A/S Amdt _____ to A/S Sub Amdt _____
 A/S Amdt _____ to A/S Amdt _____ to A/S Sub Amdt _____

- Be recommended for:
- Passage Adoption Confirmation Concurrence Indefinite Postponement
 - Introduction Rejection Tabling Nonconcurrence

<u>Committee Member</u>	<u>Aye</u>	<u>No</u>	<u>Absent</u>	<u>Not Voting</u>
Representative J.A. Hines, Chair	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Representative Gregg Underheim	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Representative John Townsend	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Representative Stephen Freese	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Representative Terri McCormick	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Representative Sheldon Wasserman	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Representative Tamara Grigsby	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Representative Charles Benedict	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Totals: _____ _____ _____ _____





Birth Defects Prevention and Surveillance Fact Sheet

Prepared by the March of Dimes Wisconsin Chapter

PROBLEM

- Nationally, an estimated 150,000 babies are born each year with birth defects. One in five infant deaths is due to birth defects, making them the leading cause of infant mortality. According to the Department of Health and Family Services (DHFS), Wisconsin has about 69,000 births annually. Of those, it's estimated that 2,700 Wisconsin children are born with birth defects.
- Little is known about the actual causes of birth defects. While both genetic and environmental factors are believed to be the cause of some birth defects, the causes of about 70 percent of birth defects remain unknown (*National Research Council Report 2000*).
- **Fiscal Impact:** The cost of caring for infants born in 1992 with at least one birth defect or cerebral palsy was about \$8 billion. These expenses are incurred over the lifetime of such children and include the direct costs of medical, special education, and other services, as well as indirect costs of their lost work and household productivity (*Agency for Healthcare Research and Quality, 2002*).

MARCH OF DIMES POLICY:

The mission of the March of Dimes is to prevent birth defects, premature birth and infant mortality through programs of research, education, community services and advocacy. The March of Dimes supports research to identify the causes and prevention of birth defects, and supports the programs that provide the tools and resources to help researchers find lifesaving breakthroughs. This includes state surveillance and registry programs, like Wisconsin's. The Centers for Disease Control and Prevention (CDC) cite birth defects surveillance systems as a leading contributor to reducing birth defects.

WISCONSIN'S BIRTH DEFECTS PREVENTION AND SURVEILLANCE SYSTEM:

- Wisconsin's existing birth defects surveillance system collects data on the occurrence of birth defects, to identify trends, contribute to research and prevention strategies, and service delivery planning and referrals for families.
- In 2000, Act 114 was enacted, authorizing the Department of Health and Family Services (DHFS) to make improvements to the existing Birth Defects Surveillance System. The current system requires physicians and specialty clinics to report birth defects in children birth to 2 years. Hospitals voluntarily report this information.
- The following improvements to the current law (Wis. Stat. 253.12) would enhance the system's ability to assemble and analyze an accurate data set and could improve prevention and referral activities:
 - **Implement presumed parental consent.** The current consent provision prevents the integration of other data sources into the registry. A presumed consent provision is key to collecting more complete data, but still allows parents to 'opt out'.
 - **Broaden terminology in state statute** to include additional common classes of birth defects, specifically malformations.
 - **Expand program to include stillbirth data**, which is critical to scientific investigation of birth defects.
 - **Permit program to be outsourced.** Currently, the registry must be kept at DHFS, which precludes alternate models for housing and analyzing the data. Access to basic BDS data, which contains no personal identifiers and protects individual privacy, imposes limitations for researchers.

RECOMMENDATION:

The March of Dimes recommends passage of Assembly Bill 1098 to improve Wisconsin's current Birth Defects Prevention and Surveillance program to create a more comprehensive and effective system, thereby improving opportunities and eliminating obstacles for researchers committed to finding solutions and families in need.

For more information contact:

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Dear State Legislators,

I am writing to you to express my support of bill AB 1098. This legislation would help researchers find answers for families, and this is tremendously important because having these answers can empower families to make the best decisions for their lives, prevent unnecessary emotional trauma, and enhance the medical care and services that is provided to their special child.

This legislation really hits home for me because I know what it's like not to have the answers that research can provide. In 1993, my daughter, Kayla was born with a rare genetic disorder called Cornelia de Lange Syndrome (CdLS). Genetic researchers have recently found the gene responsible for this syndrome, but 12 years ago, doctors had few answers for us.

Not knowing why Kayla was born this way had a devastating emotional toll on me. I felt a lot of guilt and kept wondering if her birth defects were caused by something I had done or not done. Others wondered aloud about that too, and I felt like I was being blamed. I went through a period of denial, too, because there was no definitive test.

Without genetic testing, many families of more mildly affected children never get a solid diagnosis. If there is no diagnosis, it can hamper a family's ability to get information, support, and community services. It can also mean that physicians are unable to provide more proactive medical care.

Not having answers had a big impact on the way we planned our lives. Like many families who have children with rare birth defects, my husband, Jim, and I were concerned that it might happen again. Nobody could tell us with any certainty that it wouldn't — some families have multiple children with CdLS, even though neither parent manifests the traits of the syndrome. In most cases, however, it seems to be a fluke that happens once in a family and never again.

Jim and I had no idea which group we would fall into. We could not undergo genetic testing because they did not yet know what gene was affected. Although we wanted another child, we put our plans on hold for years, hoping that they would find the gene and thus be able to give us more guidance. I have heard of other families who wanted to have more children but, faced with the uncertainty, have opted not to. Families are making life-altering decisions without benefit of the important information that research can provide.

When we finally decided to have another baby, I had a lot of unnecessary anxiety. My second pregnancy was very stressful because I worried that this baby would also have CdLS. Looking back, I think it was sad that I was so worried during a time that should have been full of excitement and anticipation.

Collecting information about birth defects can help advance research. This will make a huge impact on the lives of the affected children and everyone who loves them. I support any legislation that can make that happen.

Sincerely,

Renee Prink
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