TESTIMONY
BIRTH DEFECTS SURVEILLANCE

Testimony on behalf of the

March of Dimes

Before the Assembly Committee on Public Health

March 28, 2007

Presented by:

Pamela Pfeffer

March of Dimes Wisconsin Chapter

State Public Affairs Committee

Good morning Mr. Chairman and members of the Committee. My name is Pamela Pfeffer. I am a mother of three and the State Director of Programs Services for the March of Dimes. Thank you for the opportunity to present testimony today on behalf of the March of Dimes in support of Assembly Bill 185. This important legislation would significantly improve Wisconsin's birth defects surveillance system.

The mission of the March of Dimes is to improve the health of babies by preventing birth defects, premature birth and infant mortality. Birth defects are the leading cause of infant death in this country, as well as a leading cause of childhood disability. It is estimated that 150,000 babies are born with a birth defect each year in the United States, which is approximately 4% of live births. It is estimated that approximately 2,700 babies are born with birth defects in Wisconsin annually.

In addition to human costs, birth defects also have significant economic costs. Lifetime costs for a child with a birth defect range from $140,000 to $700,000. For example, the lifetime cost of one case of spina

bifida is nearly $300,000. In Wisconsin, the total lifetime cost to care for all children born with birth defects is over $140 million.

By implementing effective birth defects surveillance, we can track the incidence of birth defects and identify communities and populations at higher risk. State-based birth surveillance systems assist health officials evaluate needs, deliver services, and implement and evaluate prevention programs. Epidemiological research into the causes of birth defects is a critical step in the development of cost-effective strategies to prevent birth defects.

Unfortunately, Wisconsin's current birth defects surveillance system is inadequate. The current system prevents the linkage of the birth defects registry with other vital health-related databases, which leads to inaccurate reporting. In fact, Wisconsin recently received a "D" grade for birth defect surveillance from the Trust for America's Health – a non-profit, non-partisan public health organization.

In short, changes are needed to make the current system more effective in the reporting, tracking and analysis of birth defect data. In

order to prevent birth defects, we need to know more about what causes them... and in order to identify those causes, experts must have access to specific information such as frequency of birth defects as well as other causative factors.

A fully operational state birth defects surveillance system under Assembly Bill 185 would not only help identify incidence and clusters of birth defects, but would also establish a database to contribute to the improved health status of infants and children. It would help increase access to existing services for children with special needs and increase prevention activities surrounding these special health conditions.

More specifically, Assembly Bill 185 would make the following statutory changes to improve the effectiveness of Wisconsin's birth defects surveillance system:

- Implement passive consent. This would allow parents to opt out of requirements to report identifiable information.
- Link the system with other health-related databases, such as vital record information, which is essential to a complete database and avoiding duplicate reporting.

- Provide DHFS with the authority to outsource the registry to a qualified third party – such as the Medical College of Wisconsin – to develop preventative strategies that would decrease the occurrence of birth defects.
- Include stillbirth data in the registry, which is critical to birth defects research.

At the federal level, the March of Dimes is also advocating for an increase in federal funding for the CDC's National Center for Birth Defects and Developmental Disabilities (NCBDDD) to support research and surveillance activities targeted at preventing birth defects. The NCBDDD is funding the largest case-control study of birth defects ever conducted -- the National Birth Defects Prevention Study. Nine regional centers participating in the Study identify infants with major birth defects; interview mothers about medical history, environmental exposures, and lifestyle before and during pregnancy; and collect DNA samples to study gene-environment interactions. With nearly 10 years worth of data and samples collected this study is a rich source of information on possible causes of birth defects.

As I am sure you are aware, the NCBDDD also provides funding to assist states with community-based birth defects surveillance systems, programs to prevent birth defects, and activities to improve access to health services for children with birth defects. Surveillance forms the backbone of a vital, functional and responsive public health network. The March of Dimes will continue to work to secure an increase in federal funding for these programs.

The March of Dimes would urge you to support AB 185 and help enhance birth defects surveillance in communities throughout Wisconsin.

Again, I would like to thank you for your time. The volunteers and staff of the March of Dimes look forward to working with you in the future to help prevent birth defects in Wisconsin.

Contact: Pamela Pfeffer

March of Dimes
Saving babies, together

Wisconsin's Birth Defects Prevention and Surveillance System

Prepared by the March of Dimes Wisconsin Chapter (1-800-747-DIME)

PLEASE SUPPORT AB 185 TO IMPROVE WISCONSIN'S BIRTH DEFECTS PREVENTION AND SURVEILLANCE SYSTEM

Birth defects are the leading cause of infant death in the United States.
One in five infant deaths is due to birth defects. In Wisconsin, of the 68,000 births annually, we believe there are approximately 2,700 hundred children born with birth defects. However, we don't know for sure because of the lack of reliable data currently being collected.

Birth Defects Surveillance is a good investment in prevention for Wisconsin with long-term potential savings, not to mention the prevention of emotional hardship experienced by families.
Lifetime costs for a child with a birth defect range from $140,000 to $700,000. For example, the lifetime cost of one case of spina bifida (now potentially preventable with folic acid) is close to $300,000. These costs can impact the state through Medicaid, catastrophic insurance costs or uncompensated health care costs.

An effective BDS system will help Wisconsin meet its public health objectives.
The causes of up to 80 percent of birth defects are unknown. Accurate and complete information will assist Wisconsin in evaluating and developing effective prevention strategies for birth defects as well as develop research projects to help identify some of the currently unknown causes. Outcome measurement information can be used to design targeted intervention strategies to help the state address public concerns about possible environmental causes of birth defects.

Wisconsin received a "D" from the Trust for America's Health in their recent nationwide Birth Defects Report.
Wisconsin – typically a "bellwether" state in the health arena – is falling behind the 41 other states whose BDS programs received the same grade or better than Wisconsin's.

Your constituent's privacy and confidentiality is relentlessly protected.
The proposed changes to Wisconsin's Birth Defects Prevention and Surveillance System under AB 185 would make the program more efficient and complete and include strict protections to guard the privacy and confidentiality of Wisconsin's citizens. The protections exceed those mandated by the federal government.

The current Birth Defects Prevention and Surveillance System (Wis.Stat.253.12) is flawed.
The proposed legislation will work to reduce program obstacles, resulting in a more comprehensive surveillance system. The current system prevents linkage of the Birth Defects Registry with other health-related databases (e.g., birth records, hospital discharge data). For a passive surveillance system, such linkage is necessary to ensure complete data and avoid duplicate reporting. The proposed changes will correct these deficiencies, in part by allowing parents the opportunity to opt out of the inclusion of identifying data in the Birth Defects Registry rather than insisting on an active consent for inclusion.

For more information contact Pam Pfeffer, State Director of Program Services, March of Dimes at 414-778-3500 or ppfeffer@marchofdimes.com

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WI Birth Defects Prevention & Surveillance Act

Assembly Bill 185

Wisconsin Birth Defects Prevention and Surveillance Program:

The current Birth Defects Prevention and Surveillance System (BDS) was established in May 2000 to create a confidential birth defects registry comprised of birth defects found in infants and children who are diagnosed or treated by a physician, pediatric specialty clinic or hospital. Under the law, physicians and pediatric specialty clinics are required to report birth defects in infants and children (up to two) to the Birth Defects Prevention and Surveillance System Registry. Information collected and included in the BDS Registry must be used to develop preventative strategies to decrease the occurrence of birth defects.

Why was the BDS Program created?

To prevent birth defects, we need to know more about what causes them. To identify causes, doctors and scientists need to know the frequency of individual birth defects and need to compare the occurrence of specific birth defects to the presence of potential causative factors. Wisconsin's BDS program allows that information to be collected. The National Centers for Disease Control and Prevention cites birth defects surveillance systems as a leading contributor to reducing birth defects.

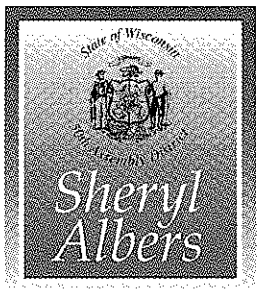
Why are changes to the BDS program needed?

Birth defects are the leading cause of infant death in the United States. One in five infant deaths is due to birth defects. In Wisconsin, approximately 2,700 children are born with birth defects. The Wisconsin Birth Defects Surveillance program can be a valuable tool in tracking birth defects and identifying trends across the state, but changes are needed to reduce obstacles that make it less effective.

The proposed changes will insure Wisconsin's registry is more comprehensive, accurate and complete. It will also improve opportunities and eliminate obstacles in the study of the prevention and causes of birth defects. The bill will specifically enhance the current BDS program by:

- **Implementing presumed parental consent**. This provision would require parents (of children with birth defects) to opt-out of the reporting program instead of opting-in, which is current law. This will allow for more widespread collection of data and allow the system to be linked to other health-related databases. Such linkage is necessary to ensure complete data and avoid duplicate reporting.
- **Expanding the program to include stillbirth data and vital records.** This data is critical to the identification and scientific investigation of birth defects and their ultimate prevention.
- **Expanding the definition of "birth defect" to include malformations.**
- **Permit DHFS to contract with a qualified third-party to develop preventive strategies for birth defects.** Currently, the registry must be analyzed for preventative strategies only by the Department.

Passage of the Birth Defects Prevention & Surveillance Act is crucial, as it would significantly improve the BDS program. It will allow for more effective and efficient data collection and evaluation, which will help physicians and scientists in their mission to find the cause and ultimately prevent birth defects.



MEMORANDUM

TO: Members, Assembly Committee on Public Health

FROM: Rep. Sheryl Albers

DATE: March 28, 2007

RE: Amendment to AB 185 for your consideration

After reading AB 185 I have a couple of concerns that I hope you will raise questions about during the public hearing today. I have shared the amendment with Rep. Townsend, the author, prior to this distribution.

My two concerns relate to first the release of information to unauthorized parties and second as a result of the release of this information to parties authorized or unauthorized that a family may be "black listed" in some way.

Thank you for your consideration.

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District: Box 339 Country Cove Estates • Golf Course Road • Reedsburg, Wisconsin 53959 • (608) 524-0022

ASSEMBLY AMENDMENT ,

TO 2007 ASSEMBLY BILL (LRB–0947/1)

At the locations indicated, amend the bill as follows:

1. Page 4, line 25: after that line insert:

"**SECTION 6h.** 111.91 (2) (hm) of the statutes is created to read:

111.91 **(2)** (hm) Disciplinary procedure under s. 230.34 (5).

SECTION 6p. 230.34 (5) of the statutes is created to read:

230.34 **(5)** If the department of health and family services determines that reasonable suspicion exists to investigate an employee for a violation of s. 253.12 (3) (a) 1. c. while that employee was employed by the department of health and family services, the employee may be suspended with pay or reassigned to other state employment if a vacant position is available at comparable pay. No later than 6 months after the date on which the employee was suspended or reassigned, the department of health and family services shall complete the investigation. If the

department of health and family services determines that the employee violated s. 253.12 (3) (a) 1. c., the employee may be terminated.".

2. Page 7, line 16: after "c." insert "Any material released by the department to the entity under the contract may be used only for the performance of this development and may not be used by an insurer, as defined in s. 600.03 (27), or by a health care provider, as defined in s. 146.81 (1). The department may not under this subd. 1. c. reveal information that may specifically identify the subject of a report made under sub. (2).".

3. Page 10, line 5: after that line insert:

"**SECTION 28m. Initial applicability.**

(1) The treatment of section 230.34 (5) of the statutes first applies to an employee who is affected by a collective bargaining agreement that contains provisions that are inconsistent with that section on the day on which the collective bargaining agreement expires or is extended, modified, or renewed, whichever occurs first.".

(END)