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Details:

(FORM UPDATED: 07/12/2010)

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

**2007-08**

(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)                      (**ajr** = Assembly Joint Resolution)  
(**sb** = Senate Bill)                              (**sr** = Senate Resolution)                      (**sjr** = Senate Joint Resolution)
- Miscellaneous ... **Misc**

## Vote Record Committee on Public Health

Date: 2/20/08

Moved by: Schneider

Seconded by: Benedict

AB 740 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

Committee Member

|   | <u>Aye</u>                          | <u>No</u>                | <u>Absent</u>                       | <u>Not Voting</u>        |
|---|-------------------------------------|--------------------------|-------------------------------------|--------------------------|
| <b>Representative J.A. Hines, Chair</b> | <input type="checkbox"/>            | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> |
| <b>Representative Leah Vukmir</b>       | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>            | <input type="checkbox"/> |
| <b>Representative Joan Ballweg</b>      | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>            | <input type="checkbox"/> |
| <b>Representative Terry Moulton</b>     | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>            | <input type="checkbox"/> |
| <b>Representative Lee Nerison</b>       | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>            | <input type="checkbox"/> |
| <b>Representative Charles Benedict</b>  | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>            | <input type="checkbox"/> |
| <b>Representative Sheldon Wasserman</b> | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>            | <input type="checkbox"/> |
| <b>Representative Marlin Schneider</b>  | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>            | <input type="checkbox"/> |
| <b>Representative Spencer Black</b>     | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>            | <input type="checkbox"/> |

Totals: \_\_\_\_\_

Motion Carried

Motion Failed





State of Wisconsin  
**Department of Health and Family Services**

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Jim Doyle, Governor  
Kevin R. Hayden, Secretary

February 13, 2008

TO: Assembly Committee on Public Health  
FROM: Katie Plona, DHFS legislative liaison  
RE: Assembly Bill 740

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Good morning. I'm Katie Plona, legislative liaison for the Department of Health and Family Services. With me today is Laura Stephenson, who is the Program Director for the Wisconsin Cancer Reporting System in the Division of Public Health. Senator Carpenter and committee members, thank you for the opportunity to testify in favor of Assembly Bill 740.

I would like to use my time before the committee to provide some background about the cancer registry at DHFS.

The Wisconsin Cancer Reporting System, established in 1976 by the Legislature, is Wisconsin's only statewide cancer registry. It has 7.9 FTE/LTE/contract positions that are 75-percent funded through a federal cancer grant and 25-percent funded by GPR to meet the federal grant's requirement for state "maintenance of effort" and matching funds. The program has been serving the state of Wisconsin in a number of valuable ways for more than 30 years:

- We have provided aggregate data on the burden of cancer in Wisconsin through its annual report and other specifically focused reports and studies;
- Provided de-identified datasets to researchers in Wisconsin and around the country for more in-depth research;
- Provided confidential information for approved research, as allowed by the current Wisconsin statute;
- Provided aggregate data to include in national and international publications.

Currently, identifiable data from the cancer registry is not available outside of DHFS with two exceptions: to a nationally recognized tumor registry, which is the National Program of Cancer Registries within the Centers of Disease Control and Prevention or to another state central cancer registry. Our registry would contain information about patients who are residents of another state if they have had their cancer diagnosis in Wisconsin.

The restriction on data release was a standard precaution in the 1970s and 1980s when our system started. But, it has proven to be increasingly insufficient to meet the needs of qualified cancer researchers in Wisconsin and around the country. The cancer research arena has broadened in the last decade, but Wisconsin's cancer laws have not been updated to meet those needs.

In 1992, the U.S. Congress passed Public Law 102-515, allowing for the creation of a National Program of Cancer Registries. The main purpose of this law was to establish central cancer registries in states that did not have one and to improve and enhance cancer registries that were already in existence, such as Wisconsin's registry. In the area of cancer data release, the Public Law, under criterion VI, requests that state registries have "a means by which confidential case data may in accordance with State law be disclosed to cancer researchers for the purposes of cancer prevention, control and research."

Many states established cancer registries through this law, and when doing so, wrote statutes that allowed access to confidential cancer data for qualified researchers following the guidelines in the federal law. AB 740 allows for increased release while still protecting the confidentiality of the data as defined in other parts of the current state statute.

We have worked closely with the bill's authors, key research institutions and organizations in Wisconsin to develop the specific provisions and definitions used in AB 740. We greatly appreciate how receptive they have been to work with the Department.

We support this legislation because it will increase opportunities for important research. Additionally, there are key provisions in the bill that I would like to highlight:

1. AB 740 authorizes 1.0 FTE in the registry to conduct the work needed to meet the increased demands for data this legislation will generate. Currently, the Wisconsin registry is the fourth lowest staffed registry in the country. The Wisconsin staff's current focus is to meet the national requirements for data completeness, timeliness and quality. Allowing increased access to data for research without providing the necessary staff to complete the requests would put an undue burden on current staff and the completeness, quality and timeliness of data requests would suffer. Revenue the Department collects from researchers for this data would be used to pay back the general fund.

This GPR-funded position will also improve the registry's ability to meet the CDC grant's maintenance of effort requirement that I mentioned earlier and the additional required match component. The requirement is one dollar of non-federal funding for every three dollars of federal funding. In addition, the proposed annual \$90,000 allocated to this position will allow the registry, based on the 3:1 match calculations, to annually request three times that amount, \$27,000, in additional federal funding in future grant applications. Unfortunately, additional federal funding is limited and not a guarantee. Still, this legislation creates the potential for Wisconsin to receive more federal funds.

2. AB 740 defines "research" and "researcher" in a way that meets federal standards for these definitions.
3. AB 740 includes specific requirements for materials to be provided to the Department when requesting data that inform the Department about the nature of the research request, the protections for the data and the researcher's qualifications.
4. It creates civil and criminal penalties for misuse of the data.
5. It includes language that follows the federal Public Law 102-515 criterion for release of confidential data to researchers by limiting release only for the purpose of studying cancer, cancer prevention or control.
6. It does not alter any other part of the statute that discusses confidentiality of data.
7. It includes language protecting the data from open records requirements.

Thank you again for the opportunity to testify in favor of AB 740. Laura and I are available to answer any questions you may have.





**To:** Assembly Committee on Public Health  
**From:** Amy Trentham-Dietz, PhD  
**Subject:** Assembly Bill 740  
**Date:** February 13, 2008

Hello. My name is Amy Trentham-Dietz. I am an associate professor in Population Health Sciences at the University of Wisconsin-Madison and a Member of the Paul P. Carbone Comprehensive Cancer Center.

There are a few points I would like to bring to your attention today in support of Assembly Bill 740, also called the Cancer Research Advancement Act.

I would like to first testify in support of the tremendous value of the Wisconsin Cancer Reporting System. This population registry is the only way we have to monitor the burden of cancer in the state. Trends in the Wisconsin data tend to mirror the ones observed in national data. This is reassuring because this shows that our data are not limited by incomplete reporting that invalidates its use for research or surveillance. Our high-quality data allow us to monitor for unexpected increases or decreases in the numbers of cancer cases here at home. For example, we can assess how cancer rates are different according to geographic location within the state. Past studies have examined where women were most likely to be diagnosed with advanced-staged breast cancers within Wisconsin, showing us where screening mammography efforts should be targeted so that more women have their breast cancers diagnosed earlier to improve their chances for long-term survival and cure.

My second point is that I believe Wisconsin citizens are supportive of expanding cancer research. I have been doing cancer research at the University of Wisconsin, working closely with registry staff, for over a decade. I routinely feel grateful that I am conducting research in Wisconsin because of the tremendous support that cancer patients provide for cancer studies. We often achieve 70, 80, or even 90% participation rates in our studies because men and women around our state are committed to reducing the burden of cancer. High participation rates are critical so that we can be assured that our study groups are representative of the targeted patient groups and our studies are not biased because they are missing important subgroups of people. Our study participation rates are the envy of researchers in other states.

Lastly, I want to urge you to support the fiscal note. The staff members at the registry are deeply committed to fulfilling the registry's mandate to collect data and provide data summaries to the Centers for Disease Control (the CDC) and the North American Association of Central Cancer Registries. The Wisconsin registry is understaffed relative to other comparable sized states and even states with smaller populations. While data collection and data utilization are both

important goals for the registry, providing datasets to researchers is necessarily the second step, with registry staff concentrating most of their efforts on data collection and consolidation. Last year I submitted 7 data requests to the registry corresponding to research studies supported by the National Cancer Institute, the CDC, the Susan G Komen for the Cure Breast Cancer Foundation, the Wisconsin Partnership Fund for a Healthy Future, and the Carbone Cancer Center. It has taken 3 months, 6 months, or even longer to receive the data for these requests. I want to emphasize that I believe the registry staff are dedicated to supporting research and would have provided these data to me sooner if they only had the time. It is essential that the fiscal note is included with this bill. In light of current delays in data requests, I am concerned that the registry will not have the capacity to handle an expansion in access to the cancer data for research purposes.

As we in Madison and Milwaukee and LaCrosse and elsewhere around the state expand our efforts to support public health, I hope that you will support both this bill and its associated fiscal note because Assembly Bill 740 will translate to improvements in our ability to prevent, detect, and treat cancer all across Wisconsin.

Thank you for your attention.







February 13, 2008

Assembly Public Health Committee  
Wisconsin State Capitol  
Madison, WI 53707

Dear Chairman Hines and Members of the Assembly Public Health Committee:

Please allow me to introduce myself, I am Dr. Humberto Vidaillet, a cardiologist specializing in electrical disorders of the heart and Director of Marshfield Clinic's Research Foundation, part of the Marshfield Clinic system. I am writing on behalf of the Marshfield Clinic system in support of *Assembly Bill 740-Cancer Research Advancement Act*.

To briefly tell you a bit about the Marshfield Clinic system:

- Marshfield Clinic is a 501(c) (3) not-for-profit health care system.
- Our mission is "to provide high-quality health care to all who access our system regardless of payer source; to engage in basic science and clinical research to improve patients' lives; and to train the next generation of physicians through undergraduate and graduate medical education."
- Marshfield Clinic is a physician-led, not owned, integrated outpatient health care system with a 20-county primary service area in North Central Wisconsin.
- We currently have 41, soon to be 47, clinics and facilities in this region, with almost 800 physicians and approximately 6,500 additional employees.
- We provide primary, secondary, and tertiary health care to all who access our system. In FY 2007, Marshfield Clinic saw approximately 365,800 unique patients.

An integral part of the Marshfield Clinic System is the Marshfield Clinic Research Foundation. Founded in 1959, the Research Foundation was initially involved in the diagnosis of agricultural related diseases. Currently there are 24 full-time PhD Scientists and 160 support staff involved in over 400 research studies funded by various Federal and State Agencies including the National Institute of Health, National Cancer Institute, and Centers for Disease Control.

Marshfield Clinic has approximately 30 medical, pediatric, surgical, and radiation oncology specialists on staff who actively participate in oncology clinical trials. Approximately 400 Marshfield Clinic system patients are enrolled annually in cancer clinical trials. Those 400 patients and other patients from other centers in the state and outside of the state are participating in over 100 clinical trials, which continue to seek patient inclusion.

Assembly Public Health Committee  
February 13, 2008  
Page Two

For more than 30 years, Marshfield Clinic and Marshfield Clinic Research Foundation have participated in the Community Clinical Oncology Program sponsored by the National Cancer Institute. This initiative was founded to translate state of the art cancer research to community clinical practices in rapid times spreading high-quality cancer care throughout Wisconsin beyond our 2 major metropolitan areas.

AB 740, authored by Rep. Schilling and Sen. Sullivan, will allow researchers and clinicians involved in cancer care in Wisconsin to access with appropriate safeguards the Wisconsin Cancer Reporting System (WCRS). This data will allow researchers and clinicians in Wisconsin to track cancer clusters in parts of the state, to access incidence and prevalence data statewide of rare and common forms of cancer and to follow patients' response to therapy.

Having this kind of population-based cancer data available will help Wisconsin achieve part of its Healthy Wisconsin 2010 and beyond goals of reducing the incidence of cancer and deaths due to it.

AB 740 will make critical state based cancer statistics accessible to a larger cadre of cancer treatment specialists and researchers.

Marshfield Clinic urges you to support AB 740.

Sincerely,

Humberto Vidaillet, M.D.  
Director of Marshfield Clinic Research Foundation

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Date: Wednesday, February 13, 2008

To: Representative J.A. Hines, Chair, and Representative Committee on Public Health,

From: J. Frank Wilson, M.D., FACR, FASTRO

Re: Assembly Bill 740

Representative Hines and Representative Colleagues:

I am writing to express support for Assembly Bill 740. This bill, combined with the fiscal note attached, plays a critical role in supporting cancer research, prevention, and care in Wisconsin.

In 1976, the Wisconsin Cancer Reporting System was established to track all cancer cases diagnosed in the state of Wisconsin. Hospitals and physicians are required to report cases using a standardized method. In 2002, this meant that 26,180 cases were reported. This information, along with that from the rest of the nation, forms the reference base for cancer-related research, treatment advances, and prevention efforts. As the President of the National Cancer Registrars' Association, Dr. Healy of Memorial Sloan-Kettering said, "A network of cancer registries can be our most potent new weapon against cancer. Today, thousands of people are living as a result of the type of information we collect and analyze." This includes Wisconsin citizens, *your constituents*, of all ages, colors and creeds.

The Centers for Disease Control's stated goal in supporting Cancer Registries is "to prevent and control cancer and improve patient care." This is achieved "by providing evidence-based information to physicians that is used to assess the efficacy of varying diagnostic and therapeutic methods and options and to plan, review, and update standards of care." In other words, a complete, up-to-date, and accessible registry is essential for the citizens of our state to receive proven preventive services, the most effective screening measures, and optimal life-saving treatment. This bill would play a crucial role in protecting the health of Wisconsin citizens by allowing researchers access to the information in the registry while also maintaining the privacy of individuals. It also adds one FTE to the WCRS staff. This final component is absolutely critical for several reasons:

- The Wisconsin Cancer Reporting System staff have done and are doing an outstanding job and were recognized in 2004 by the CDC for their work; they are already working as efficiently as possible.
- Wisconsin's registry has the fifth highest caseload per staff among all states with over 4000 cases a year for each staff member being registered. This is twice the national average.
- Minnesota has slightly fewer cancer cases each year, but over four times the staff that Wisconsin does. Other states with comparable caseloads are Alabama with 1800 cases per staff member, Missouri with 1700, and Arizona with 1600.
- Understaffing will limit the ability of the registry to be maintained and used effectively in several ways:



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**Bringing partners together to advance Comprehensive Cancer Control in Wisconsin**

WARF 370, 610 Walnut Street • Madison, Wisconsin 53726 • [www.wicancer.org](http://www.wicancer.org) • [wicancer@uwccc.wisc.edu](mailto:wicancer@uwccc.wisc.edu) • T 608-265-4618 • F 608-262-2425

- The current National Program of Cancer Registries funding cycle, which began last year, requires all states to employ more than one Certified Tumor Registrar (CTR). Wisconsin currently can not meet this standard, jeopardizing our federal funding;
- Reporting in Wisconsin varies between facilities because, unlike New York and other states, we do not require that every cancer case report be prepared by a CTR. This additional position would improve data quality and thereby improve research outcomes;
- WCRS staff provide assistance in training and electronic reporting and would be even more involved in monitoring and education with the measures contained in this bill. Current staff levels are simply insufficient to do all of this with the quality and timeliness that a necessary function of this magnitude merits.

The contents of this bill, including the addition of a staff member, are also consistent with the Wisconsin Comprehensive Cancer Control Plan. The addition of a staff member and the availability of data to researchers are critical in achieving several priorities identified in the Plan. Among the most important of these is improved collection of data on racial and ethnic minorities. African American, Latino, and Native American patients bear a disproportionate burden of cancer mortality. In particular, they are less likely to be alive five years after a cancer diagnosis. If we are serious about closing health disparities in the State of Wisconsin, we must support legislation such as this that gives researchers, public health officials, and administrators the tools they need to provide better care for minority populations.

Members of the committee, please support this bill, including the addition of one FTE to the WCRS staff. It is an investment in the health and future of the citizens of Wisconsin.

Sincerely,

*J. Frank Wilson M.D.*

J. Frank Wilson, M.D., FACR, FASTRO  
 Immediate Past Chairman, Wisconsin Cancer Council  
 Chairman and Bernard & Miriam Peck Professor of Radiation Oncology  
 Director Emeritus, Cancer Center  
 Medical College of Wisconsin



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**Testimony of State Representative  
Steve Wieckert**

**Assembly Bill 740 – Cancer Registry**  
*Assembly Committee on Public Health*  
*Room 328 Northwest – February 13, 2008*

Thank you, Mr. Chairman and members of the committee for holding a hearing on this important subject.

In so many ways, cancer is public enemy number one for our citizens' health and many times our citizens' survival.

This bill would promote and encourage the advancement of cancer research by allowing researchers greater access to more specific information on the existing cancer registry in Wisconsin which is officially referred to as the Wisconsin Cancer Reporting System.

Especially in three general areas regarding the background of the patient where they were living, their age, etc. as well as the type of cancer they have and the stage that it is in and third the type of treatment that is being administered is all valuable in understanding the causes and the effectiveness of cures of cancer.

This bill has adequate safeguards to make sure this information is used appropriately and will allow cancer researchers more information and research data needed in the fight to find ways to cure and prevent cancer. This bill has a broad coalition of democrats and republicans from both houses. I thank Sen. Sullivan and Rep. Schilling for doing the research necessary to put this bill together in such an efficient way.

I would be happy to answer any questions.







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Wisconsin State Senate

**Testimony of Senator Jim Sullivan**  
**Assembly Bill 740**  
**Assembly Committee on Public Health**

Good morning committee members, and thank you for your attention to Assembly Bill 740, legislation that will help researchers study cancer and cancer prevention.

The Wisconsin Cancer Reporting System (WCRS) is a repository for all diagnoses of cancer and precancerous (tumors of the central nervous system) conditions in Wisconsin. It was established in 1976 by the Wisconsin Legislature, and continues to operate today under rules established over thirty years ago.

Assembly Bill 740 will update Wisconsin law to allow the Wisconsin Cancer Reporting System to provide confidential data to qualified researchers for the purpose of cancer research, prevention and control. Currently the WCRS is only able to provide researchers that do not meet the current statutes access to de-identified data that is not always sufficient for their research. Sometime researchers need more specific data to complete and validate their research, and that is the purpose of Assembly Bill 740. Assembly Bill 740 will allow the WCRS to release confidential, patient-identifiable data to qualified researchers for the purpose of studying cancer or cancer prevention.

Numerous safeguards are built in to ensure the information is protected and only used for the purpose of studying cancer. These safeguards include a rigorous application process, approval by an institutional review board (IRB), and civil and criminal penalties for misuse of data.

Organizations from around the state have endorsed this legislation, including the American Cancer Society, Medical College of Wisconsin, Gunderson Lutheran Health System, University of Wisconsin School of Medicine and Public Health, Marshfield Clinic, Wisconsin Cancer Council, Wisconsin Medical Society, Wisconsin Collaborative for Healthcare Quality, St. Joseph's Hospital, Wisconsin Association of Health Plan, Lakeshore Medical Clinic, Medical Associates Health Center and more.

Medical research has been a source of great pride in Wisconsin, and this bill will help move research towards the ultimate goal: a cure. Wisconsin is one of only five states that does not currently release patient-identifiable data. We all want to find a cure for cancer, and it is time for Wisconsin to join other states and give our researchers the tools they need in order to do their work. I ask for your support of Assembly Bill 740.





Good morning. I am Linda Roberts, a member of Wisconsin Breast Cancer Coalition (WBCC).

The Wisconsin Breast Cancer Coalition is a non-partisan, grassroots advocacy and educational organization whose mission is to eradicate breast cancer.

The Wisconsin Breast Cancer Coalition, based in Milwaukee, works throughout the state to educate and inform Wisconsin residents about breast cancer. This includes legislators and public policy makers.

WBCC is a member of the National Breast Cancer Coalition (NBCC), another non-partisan, grassroots advocacy group which advocates for breast cancer legislation at the federal level.

The National Breast Cancer Coalition's members include more than 500 organizations and over 60,000 individuals. The Wisconsin Breast Cancer Coalition is one of these member groups.

One of the National Breast Cancer Coalition's accomplishments is the nearly \$2 billion from 1991 in funding to the Department of Defense's Breast Cancer Research Program. Out of the DoDBCRP came the drug Herceptin. This drug is the only defense for the particularly aggressive HER-2/Neu positive breast cancer.

I am here today to indicate WBCC's strong support for this legislation.

We realize that breast cancer is a complex disease and that we need all the potential "breast cancer-fighting tools" we can get into our toolbox.

Armed with more information to discover the cause – be it genetics or environmental or some combination of these and other factors –and a cure, this information is vital to eradicate breast cancer.

The WBCC urges passage of this bill to law.

On a personal note, I speak for my late sister Nancy Louise DalBesio who died of HER-2/Neu positive breast cancer at the age of 44. I know Nancy would welcome this legislation so her daughters, who are now in their early 20s, will not have to pay the same price she did.

Our website is: [www.standupandspeakout.org](http://www.standupandspeakout.org)

The National Breast Cancer Coalition website is: [www.stopbreastcancer.org](http://www.stopbreastcancer.org)

Thank you.