Congressman David Obey: Champion of Health Care Reform and Cancer Research

Kathleen Harris, NBCC Field Coordinator-WI

On May 5, 2010, WBCC received an email from Mr. Obey's office—the shocking news that Chairman Obey will not run for re-election was just made public. The news sent shock waves across the country. We think few outside the breast cancer advocacy community would know or feel our own sense of loss—a champion who cared about families experiencing a health care crisis and research to eradicate cancer.

By now, all who follow what happens in Washington, DC, know Mr. Obey is the third most senior member of Congress. He was first elected in 1969 at the height of the Vietnam War. He won twenty straight races, prevailed through wars, economic crises, and other turmoil under eight presidents. He has served his country and the people in his district in WI, for forty one years.

It has been said by some in Washington, that Mr. Obey's decision not to run for re-election was due in part to the passage of health care reform—a long standing priority of his.

For sixteen years, National Breast Cancer Coalition Team Leaders from WI and our state delegation have been meeting with Mr. Obey and his staff to discuss funding for research that would ultimately cure or prevent breast cancer. For the last five or six years, the focus of our discussion has included another top priority: Access to Quality Care for All.

We presented NBCC’s Core Principles and Framework for what health care reform should look like. We had long and thoughtful discussions with his staff, who listened intently to what we had to say. Though we may not have been in perfect agreement, we know first hand, Mr. Obey's intent was to work to make health care accessible for all Americans.

Many of us involved in health care reform turned to CSPAN to watch Mr. Obey preside over the House as the chamber passed the health care bill. Mr. Obey has mentioned his role in this process as a great privilege.

As House Appropriations Committee Chairman, Mr. Obey has oversight of more than $1 trillion in annual federal spending— a task with constraints and many demands. But when it comes to policy decisions, he favors policy rooted in Midwestern values. We know Mr. Obey as a plain spoken man, with a certain disdain for the ways of Washington. We know this man as one who doesn't seem to strive for what's best for him but rather for the right thing to do.
President’s Letter

Warm wishes as we welcome summer. After several years of serving in various capacities, it seems I just stepped into this role and it’s already almost half over. I hope I have been able to impart some valuable insight that will continue to be helpful to WBCC for years to come.

I am proud to serve as president of the only breast cancer group in Wisconsin that remains active in promoting education and advocacy beyond the media sound bytes about breast cancer. The Wisconsin Breast Cancer Coalition continues its collaboration with other organizations; ensuring that legislators and other policy makers hear from the patient’s perspective.

This has been a very busy year for WBCC. We recently traveled to Washington DC to attend The National Breast Cancer Coalition Annual Advocacy and Training Conference. This year Wisconsin was represented by 43 advocates from our state. The conference was very insightful. The conference’s theme, “Peeling back the Pink,” serves as a vehicle to continue to empower breast cancer advocates.

I understand and believe in the need for education relative to breast health and breast cancer. I have a passion for mentoring women who have been affected by this awful disease. I am a 17 year breast cancer survivor, who often presents educational programs to women’s groups, in an attempt to bring awareness. I encourage them to get to know their bodies and be aware of their risk. I give them pretty pink ribbon pins, with hopes that they will continue to pass the message of awareness along to other women.

Pink Ribbon pins are now and will probably continue to be a symbol of breast cancer awareness. I think the color pink was chosen because breast cancer affects many more women than it does men. Our culture supports pretty in pink for girls. As a breast cancer survivor, whose treatment included a left mastectomy followed by 6 month of IV chemotherapy and years of Tamoxifen, I can assure you, there is nothing pretty about breast cancer.

When I think of this theme “Peeling back the Pink,” it raises the bar for me. I will continue to raise awareness and give beautiful pink ribbon pins to women because I certainly understand the need for Breast Health Education and Awareness. I also understand it will take much more than awareness to end this disease forever.

Advocating for research dollars must continue to be high priority for all of us. The only way to achieve safer, more effective treatments for breast cancer is to understand that this will only happen through increased research. Wisconsin Breast Cancer Coalition will continue to bring the voices of the people in Wisconsin to our legislators in Washington DC.

Education, Awareness, and Advocacy are all part of the arsenal needed to rid the world of breast cancer forever.

The theme of “peeling back the pink” helps me to understand how much more I have to do as a committed advocate.

Bonnie Anderson
Beyond the pink ribbon® Advocacy Seminars traveling the State

By WBCC Executive Director, Dawn Anderson

“I have come to the conclusion that politics is too serious a matter to be left to the politicians.” – Charles de Gaulle

The WBCC – as a grassroots advocacy organization - knows this only too well! We know that our elected representatives, despite their best intentions, often just don’t have all the facts, have not heard from their constituents directly on important matters, or sometimes need to be persuaded in a more favorable direction.

The success of our grassroots network lies in having well trained advocates who are passionate about the issue at hand. There is a lot more to working with legislators and other policy makers than just sending an email or signing a petition. To get important work done, an advocate needs to be well informed on the issue, have a good grasp on how the legislative process works, know how best to approach their legislators’ offices and make their point, and the best ways to follow up with those offices. To that end, we developed a program to train participants in the art and science of effective advocacy.

“Beyond the pink ribbon®” Advocacy Seminars have been held in 5 parts of the state to date – Milwaukee, Racine, Appleton-area, Madison, and most recently in Green Bay. Each seminar includes a panel discussion with area legislators and seasoned “activists”. Participants receive an Advocacy Tool Kit and participate immediately by becoming a part of our Legislative Alert Network.

Last year, we were fortunate to receive a substantial Programmatic Capacity Building grant from the National Breast Cancer Coalition Fund, which has allowed us to improve our outreach and training materials. It also allowed us to include a second level of more in-depth training for participants interested in taking their advocacy the next step. With the help of consultants, Prown and Associates, we have greatly improved and expanded this program.

Future “Beyond the pink ribbon®” seminars are planned for September 18 in La Crosse and October 23 in Milwaukee. Please contact us if you’d like to pre-register for either seminar, or watch for more news on our website www.standupandspeakout.org.

left to right: Ashley Ramaker, Congressman Steve Kagen’s Field Representative; Kathy Hansen; State Representative Penny Bernard Schaber; Kris Miller; Sarah Thomsen, Action 2 News Anchor

Obey

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NBCC and WBCC (Wisconsin Breast Cancer Coalition) celebrate Mr. Obey’s long career in public service, his commitment for working to pass health care reform that would benefit all Americans, especially middle class families, and for his long standing support for funding research to eradicate breast cancer. Because of his years of support, NBCC voted to award Mr. Obey its Congressional Award, a decision made prior to his retirement announcement. The award will be presented to him in Washington, May 25th.
The North Carolina Breast Cancer Study Presentation

By Dr. Michelle DeBose

(Presented by Dr. Bob Millikan – Principal Investigator, Lisa Lacks – Nurse Interviewer and Sara Williams – Recruitment Specialist)

This study is one of the largest studies of breast cancer ever undertaken, and one of the first studies to include younger women, African American women, and women from the rural South. The study is especially important because of the addition of the breast cancer advocates from Sisters’ Network. Sisters’ Network is the only National Breast Cancer survivorship organization across the country.

For over 20 years we have known that breast cancer mortality is higher in African American women and younger women. Using data collected from Carolina Breast Cancer Study (CBCS) between 1993 and 2001, they found younger women and African American women have higher rates of basal-like breast cancer. Basal-like breast cancer is a form of triple negative breast cancer (ER-negative, PR-negative, HER2-negative).

In order to better understand the causes of basal-like breast cancer in African American and white women, they began to enroll an additional 2000 breast cancer patients in their study. Since the very beginning of their study, breast cancer patient advocates have played a strong role in the CBCS. Since 1993, local breast cancer survivors meet with the CBCS staff to develop outreach materials, informed consent documents, questionnaires, and other study materials. Advocates help write summaries of our research findings to share with the public. Most importantly, advocate input and assistance with community outreach have produced response rates for their study that are among the highest ever recorded for population-based studies of breast cancer.

In 2003, Sisters Network was founded in the North Carolina area, shortly afterwards, the African American breast cancer survivors joined forces with the CBCS to increase the number of African American study participants. This phase of the study is Phase III of the study, named in honor of State Senator Jeanne Hopkins Lucas. Senator Lucas was the first African-American female to serve in the North Carolina state senate, where she was a strong advocate for higher education. Senator Lucas died of breast cancer in March of 2007 at the age of 71. The Lucas Study will more than double the number of African-American breast cancer patients in the original study by enrolling an additional 1500 Black and 1500 Non-Black women by 2014, bringing the total number of CBCS participants to 2288 Black and 2520 Non-Black women. Of the 3,000 women enrolled in Phase III, there will be 750 women in each of four race and age groups: Black age 20-49, Black age 50-74, Non-Black age 20-49, and Non-Black age 50-74.

Participants are selected from a list of newly diagnosed breast cancer patients provided by the North Carolina Central Cancer Registry (NCCCR), which identifies and registers all new cancer diagnoses in the state. All participants are selected through a scientific randomization process and thus no volunteers are accepted.

The study’s primary aim is to understand why some women get certain types of breast cancer and others do not, and how racial differences in genetics, treatment, and other risk factors can influence breast cancer incidence and survival. Participants are interviewed in their homes by trained nurses regarding breast cancer risk factors and a DNA sample is taken. Participants are also asked to grant permission for researchers to access their relevant medical records. The study does not involve treatment of any kind. Additionally, the study hopes to learn more about disparities in treatment and access to care, and general quality of life.

Information for these assessments will be collected by phone, with 3 follow-up interviews conducted every 9 months after the initial in-home interview.

Questions asked in the workshop targeted, why there were no African American staff represented? What happens if they discover the women require follow up care?

The CBCS team reported they are working very hard to recruit African American staff; however, they have strong support from Sisters’ Network members who volunteer their time with the study as Breast Cancer advocates. Women are provided with the North Carolina Resource Guide for referral information and often time Lisa Lacks does additional follow up outside of the scope of her role as interviewer to follow up with the participants.

I will continue to follow the results of this study and will meet with Dr. Millikan upon my return to North Carolina in August. This was quite an informative workshop and I am sure will be invited back to see their progress.

*Dr. DeBose is a 2010 Sherry Kohlenberg Scholarship recipient who joined WBCC at the NBCC Advocacy Training Conference last month.*
WBCC joins NBCCF to “Peel Back the Pink” in Washington DC

Over 800 breast cancer activists were in attendance at the National Breast Cancer Coalition Fund’s 18th Annual Advocacy Training Conference May 22-25, including 43 from the WBCC. The conference educates and trains advocates in all areas related to breast cancer, from research design and funding, to treatment, clinical trials and public policy.

This year’s theme, “Peel Back the Pink”, was meant to teach attendees what’s really happening in breast cancer today. On the first afternoon, we heard from a panel of experts on what's new in breast cancer research, screening and treatment. Sunday featured a fantastic plenary on breast cancer and the media, with a panel including Nancy Snyderman, MD, of NBC News, and Gary Schwitzer, publisher of HealthNewsReview.org. We learned how often the media “get it wrong” in health reporting and the criteria for good health reporting. Both Snyderman and Schwitzer used the release of the revised mammography guidelines in November 2009 as an example of how the media “got it wrong” most of the time – over sensationalizing the story and not accurately reporting the Task Force’s statement.

NBCC Board Director Joy Simha, of the Young Survival Coalition, reminded us of the important role we have as advocates in helping provide accurate information to media when we’re contacted on breast cancer issues.

Later, (after attending individual workshops on topics ranging from how to expand your advocacy network to new research on MicroRNA’s and PARP inhibitors), we heard an excellent discussion on what is needed to move scientific progress forward in breast cancer research. Watch in future issues for more detailed articles on many of these workshops.

Other plenary sessions explored new ways of thinking about breast cancer as we discover more about the different types of the disease, the politics of health care reform and what it may mean for breast cancer patients and their families, and as she does every year, NBCC President, Fran Visco emphasized the urgency of our work as advocates.

Fran challenged attendees to rethink some of the efforts in breast cancer control – do we really NEED to keep pushing for more drugs, for the FDA to speed up the approval process, or for the NIH to double their budget for breast cancer? The answer may be “maybe not”. Should we be “realigning our priorities” and looking more at prevention, and environmental factors in the development of breast cancer? This is a hallmark of the National Breast Cancer Coalition – having the courage to challenge mainstream thinking about breast cancer – to educate ourselves well enough to ask these kinds of questions and then follow through on finding the answers.

Both NBCCF and WBCC offer scholarships to attend the conference. Next year’s conference will be April 30 – May 3, 2011. If you’re interested in learning more, please contact the WBCC office.
4th Annual State Advocacy Day

by WBCC Executive Director, Dawn Anderson

March 3 marked an exciting day for us at the State Capitol. Our 4th annual State Advocacy Day included some very seasoned WBCC advocates and a good number of new participants who had the privilege of sharing our policy priorities with lawmakers. New this year, we hosted a “meet and greet” in a committee room at the Capitol – legislators and their staffs were invited to drop in for coffee, pick up a packet of information, and engage our advocates in informal discussion about breast cancer issues. After that it was down to business, preparing for the afternoon’s meetings with key members of the Health, Consumer Protection, Public Health, Insurance, and Joint Finance Committees.

Amy Conlon, Director of the Wisconsin Comprehensive Cancer Control Program (WI CCCP), gave the group background on the program and explained why one of WBCC’s priorities is increased funding and policy support for the program. Funding for the program had been level at $395,000 since its inception in 1988. In the last budget, it was cut to $321,000. As one new participant noted: “Why do we only spend less than half a million dollars on control of the state’s #1 killer?”

Following Ms. Conlon’s presentation, Joseph Hoey, legislative aide to Representative Gary Sherman, gave his annual presentation on how to have the most productive meetings with legislators. This was Joe’s 3rd year working with us and we thank him for always sharing the benefit of his many years of experience in the Capitol.

A fortunate coincidence of timing occurred when Senator Julie Lassa’s office kindly invited us to be present at the signing of the BPA Free Kids Act – a bill she co-sponsored with Representative Kelda Roys, and which we supported. The bill passed in February. A small crowd, including activists from WISPIRG and other organizations watched as Governor Jim Doyle signed the bill into law.

Significantly, one of WBCC’s priorities is to improve recognition among policy makers of the role environmental toxins, like BPA, play in the development of breast and other cancers. We made clear to them, in our meetings, that “awareness” and early detection does not equal prevention. We need to look at further research, public education and regulation to move us in the direction of truly preventing breast and other cancers.

With budget work already beginning, this advocacy day was meant for us to lay the groundwork for the hard work ahead in protecting funding for priority programs such as the WI CCCP, the state’s Cancer Reporting System, and the Well Woman Program, which provides free screening and treatment to underserved and uninsured women. We will also be following the implementation of Health Care Reform initiatives at the state level. If you’d like to help us protect and improve these critical programs, please call or email us.
Behind the Scenes – 11th Annual Rare Chair Affair

By Katie Corcoran, Rare Chair Affair Co-Chair

On Saturday, October 2, 2010 the WBCC will host the 11th annual Rare Chair Affair at the Federal Court House downtown. The theme is PoP aRT!

Once again, David Caruso of Dynamic Events is the official event planner. “After the success of last year’s event, the easiest decision thus far was to stay with Dynamic Events,” states Katie Corcoran, co-chair.

The venue and theme both stemmed from Caruso. “David said he has wanted to have an event in the Federal Court House for a long time. We didn’t even know where it was, similar to plentiful of Milwaukeeans. After touring it, there was no doubt that this would be our venue,” according to Erin Calta Weide, co-chair. Caruso suggested the juxtaposition of pairing Pop Art and the Federal Court House could really set the stage for a unique and exciting experience.

The Federal Court House hosts between two and four non-profit benefits per year. The Milwaukee Federal Court House, a Romanesque Revival style building, was built in 1892-99. A massive seven-year restoration project begun in 1989 revived the building to its original condition. The work involved extensive materials research to determine original paint colors and decorative patterns for the walls and ceilings, including the original hand-painted-and-stenciled designs in a trompe-l’œil effect (an artistic illusion of realism).

The evening will consist of a silent auction, dancing, food, and the highlight of the night, the voice auction of chairs created by breast cancer survivors.

For more information, or if you are interested in volunteering the night of the event please visit www.rarechairaffair.org or call Dawn Anderson at (414) 963-2103.

Call for Volunteers

By Katie Hoida, WBCC Volunteer Coordinator

Can’t spare a dime but have some time? Many people volunteer for an organization in lieu of making monetary donations. Both are vital to the health and survival of non-profits.

WBCC has opportunities available such as sustained committee work in areas such as policy, communications/marketing and fund development, one-time “hands on” jobs, and occasional event staffing or speaking opportunities.

If you would like to learn more about volunteering for the WBCC, we will be hosting an informal Volunteer Orientation on Wednesday, June 23 at the WBCC office. Join us at 6pm to learn you can be a part of our team. Call 963-2103 to RSVP for the June 23 meeting or for future orientation dates.
WBCC MISSION
The Wisconsin Breast Cancer Coalition brings Wisconsin voices together to Stand Up and Speak Out about breast cancer with:
Education – spotlighting critical breast cancer issues
Collaboration – empowering through strategic alliances
Legislation – influencing policy making.

TO CONTACT WBCC
414.963.2103
888.295.2622
wbcc@standupandspeakout.org

“Collective Voice” to go electronic!
For many years, supporters of the WBCC have automatically received our printed newsletter on a quarterly basis. As you can imagine, our list has become quite large, while printing and postage costs have increased. Our Board of Directors, in approving a new fiscal year budget, have made the decision to scale back our printing and postage costs and only mail printed newsletters as a benefit to dues paying members. The electronic format may allow us to do more frequent, time-sensitive issues going forward and will allow you to directly link to resources such as congressional offices. It’s also easier for you to share with your friends and family!

If we have your email address in our database, you will continue to receive the newsletter in an electronic format quarterly. To ensure that you continue to receive this valuable source of information on breast cancer in Wisconsin, please send us an email at wbcc@standupandspeakout.org with your email address. You’ll automatically be added to our email list beginning with the next issue.

Alternately, if you are not a member of the WBCC, and would like to receive printed newsletters, please consider supporting us with an annual membership of $30. We’ll send you a thank you gift and you’ll be ensured free admission to our educational events such as “Beyond the pink ribbon” Advocacy Seminars and our Annual Meeting. You can join online at our website or by sending a check to PO Box 170031, Milwaukee, WI 53217.
AFFORDABLE HEALTH CARE FOR AMERICA
KEY PROVISIONS THAT TAKE EFFECT IMMEDIATELY

The Health Care Reform Bill has been passed and it has been signed into law by President Obama.

Below are some of the key provisions that will take effect immediately, under the legislative package the House passed in March 2010 (the Senate health bill as amended by the reconciliation bill). The reconciliation bill is based largely on the improvements put forward by the President's proposal – moving towards the House bill in certain critical areas.

1. SMALL BUSINESS TAX CREDITS
Offers tax credits to small businesses to make employee coverage more affordable. Tax credits of up to 35 percent of premiums will be immediately available to firms that choose to offer coverage. Effective beginning for calendar year 2010. (Beginning in 2014, the small business tax credits will cover 50 percent of premiums.)

2. BEGINS TO CLOSE THE MEDICARE PART D DONUT HOLE
Provides a $250 rebate to Medicare beneficiaries who hit the donut hole in 2010. Effective for calendar year 2010. (Beginning in 2011, institutes a 50% discount on brand-name drugs in the donut hole; also completely closes the donut hole by 2020.)

3. FREE PREVENTIVE CARE UNDER MEDICARE
Eliminates co-payments for preventive services and exempts preventive services from deductibles under the Medicare program. Effective beginning January 1, 2011.

4. HELP FOR EARLY RETIREES
Creates a temporary re-insurance program (until the Exchanges are available) to help offset the costs of expensive health claims for employers that provide health benefits for retirees age 55-64. Effective 90 days after enactment.

5. ENDS RESCISSIONS
Bans health plans from dropping people from coverage when they get sick. Effective 6 months after enactment.

6. NO DISCRIMINATION AGAINST CHILDREN WITH PRE-EXISTING CONDITIONS
Prohibits health plans from denying coverage to children with pre-existing conditions. Effective 6 months after enactment. (Beginning in 2014, this prohibition would apply to all persons.)

7. BANS LIFETIME LIMITS ON COVERAGE
Prohibits health plans from placing lifetime caps on coverage. Effective 6 months after enactment.

8. BANS RESTRICTIVE ANNUAL LIMITS ON COVERAGE
Tightly restricts new plans’ use of annual limits to ensure access to needed care. These tight restrictions will be defined by the Department of Health and Human Services. Effective 6 months after enactment. (Beginning in 2014, the use of any annual limits would be prohibited for all plans.)

9. FREE PREVENTIVE CARE UNDER NEW PRIVATE PLANS
Requires new private plans to cover preventive services with no co-payments and with preventive services being exempt from deductibles. Effective 6 months after enactment.

10. NEW, INDEPENDENT APPEALS PROCESS
Ensures consumers in new plans have access to an effective internal and external appeals process to appeal decisions by their health insurance plan. Effective 6 months after enactment.

11. ENSURING VALUE FOR PREMIUM PAYMENTS
Requires plans in the individual and small group market to spend 80 percent of premium dollars on medical services, and plans in the large group market to spend 85 percent. Insurers that do not meet these thresholds must provide rebates to policyholders. Effective on January 1, 2011.

12. IMMEDIATE HELP FOR THE UNINSURED UNTIL EXCHANGE IS AVAILABLE (INTERIM HIGH-RISK POOL)
Provides immediate access to insurance for Americans who are uninsured because of a pre-existing condition – through a temporary high-risk pool. Effective 90 days after enactment.

13. EXTENDS COVERAGE FOR YOUNG PEOPLE UP TO 26TH BIRTHDAY THROUGH PARENTS’ INSURANCE
Requires health plans to allow young people up to their 26th birthday to remain on their parents’ insurance policy, at the parents’ choice. Effective 6 months after enactment.

14. COMMUNITY HEALTH CENTERS
Increases funding for Community Health Centers to allow for nearly a doubling of the number of patients seen by the centers over the next 5 years. Effective beginning in fiscal year 2010.

15. INCREASING NUMBER OF PRIMARY CARE DOCTORS
Provides new investment in training programs to increase the number of primary care doctors, nurses, and public health professionals. Effective beginning in fiscal year 2010.

16. PROHIBITING DISCRIMINATION BASED ON SALARY
Prohibits new group health plans from establishing any eligibility rules for health care coverage that have the effect of discriminating in favor of higher wage employees. Effective 6 months after enactment.

17. HEALTH INSURANCE CONSUMER INFORMATION
Provides aid to states in establishing offices of health insurance consumer assistance in order to help individuals with the filing of complaints and appeals. Effective beginning in FY 2010.

18. CREATES NEW, VOLUNTARY, PUBLIC LONG-TERM CARE INSURANCE PROGRAM
Creates a long-term care insurance program to be financed by voluntary payroll deductions to provide benefits to adults who become functionally disabled. Effective on January 1, 2011.
Health Care Legislation Has Been Passed into Law. But Our Work is Still Not Done!

Since 2003, guaranteed access to quality care for all has been the top priority for the National Breast Cancer Coalition (NBCC). A number of years ago, NBCC began researching the best ways to approach health care reform. NBCC developed core principles, a Personal Stories Campaign and a framework as to what health care reform should look like, years before health care reform surfaced on the national agenda. The Wisconsin Breast Cancer Coalition joined the effort, working with NBCC and its grass roots networks, to make access to quality care for all a reality.

For years, we have known that the only way to accomplish our mission of eradicating breast cancer is to ensure access to quality health care for everyone. This legislation is a bold step toward that end.

Our work is not done yet. There is still much to do. Here’s what you can still do:

- Review NBCC’s Congressional Record to see how your Senators and Representative voted on Health Care Reform.
- Call your Senators and Representatives and thank them for supporting health care reform (or to express your disappointment that they did not, if that is the case).
- Read or download NBCC’s Statement on the Passage of Health Care Reform Legislation.
- Share this article or NBCC’s Statement with 10 friends and ask them to call Capitol Hill.
- Share your experience and story: “What does health care reform mean to women with breast cancer?” Participate in NBCC’s campaign, “Personal Stories, Public Action.”
- Make copies of the article in this newsletter entitled “Affordable Health Care For America: Key Provisions That Take Effect Immediately” and distribute them to family and friends and at health fairs and other events.

For more information, please see the following websites: NBCC website: www.stopbreastcancer.org
WBCC website: www.standupandspeakout.org