



**Proceedings of the  
Women In Government  
Breast Cancer Policy Workshop**

November 4-5, 2009  
Washington, DC

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## Introduction & Background

According to the National Cancer Institute, in 2009, an estimated 192,370 women will be diagnosed with, and 40,170 women will die of, breast cancer. Breast cancer is the second most common cancer in women, with skin cancer being the most common. Breast cancer is also the second leading cause of cancer death among women in the United States, exceeded only by lung cancer. The American Cancer Society estimates that one in eight women will be diagnosed with invasive breast cancer during her lifetime and one in 35 women will die from the disease. Currently, there are over 2.5 million breast cancer survivors in the United States; however, some disparities do exist for the disease. Caucasian women are more likely to be diagnosed with breast cancer than African-Americans, but African-American women are more likely to die from the disease. African-American women have a 71 percent survival rate after five years compared to an 86 percent survival rate for Caucasian women. All survivors of breast cancer face a range of issues after the initial diagnosis ranging from the devastating emotional effects, to the financial hardships due to lack of insurance coverage; and the psychological impacts on patients, their friends, and family.

Women In Government (WIG), a national, bipartisan organization of women state legislators, recognizes the continuing health concern posed by breast cancer and the unique role that legislators can play as advocates for improved access to prevention and treatment. WIG hosted our *Breast Cancer Policy Workshop – The State Legislator Role* that brought together state legislators and other key stakeholders to collaborate together on actions that must be taken in order to address breast cancer as a woman's public health issue.

*Workshop* participants included women state legislators, state agency representatives, and public health advocates - many of whom are also breast cancer survivors - to develop strategies to overcome the numerous barriers that stand in the way of effective breast cancer screening and treatment. The *Breast Cancer Policy Workshop* was held in Washington, DC on November 4-5, 2009 and included 19 policymakers and representatives from 17 states. The *Breast Cancer Policy Workshop* was sponsored by AstraZeneca.

The *Breast Cancer Policy Workshop* engaged participants in discussions and strategic planning on the current landscape of breast cancer, in addition to advances and innovations in breast cancer screenings and treatments and what necessary steps must be taken to battle this disease.

Presentations framed important discussions on:

- Treatment and diagnosis of breast cancer: advances and innovations;
- Addressing disparate populations; breast cancer in minorities;
- State legislation: screening and diagnosis, access to screening, clinical trials, and ensuring quality of care; patient navigation programs; and
- An overview of breast cancer prevalence in 2009.

At the conclusion of the *Breast Cancer Policy Workshop*, legislative participants were engaged in individual breakout sessions to discuss possible legislative projects and non-legislative initiatives that would be pursued in 2010 on breast cancer. Participants left the *Workshop* with a renewed sense of determination to improve the screening, prevention, and treatment of breast cancer as a result of the networking and educational opportunities on other state's legislative initiatives to combat this disease.

## Summary of Sessions

Wednesday, November 4, 2009

### **An Overview – Breast Cancer in 2009**

**Worta McCaskill-Stevens, MD, MS**

Program Director, Minority-Based Community Clinical Oncology Program  
National Cancer Institute  
National Institutes of Health

The National Cancer Institute (NCI) estimates that in 2009 there will be over 194,000 new cases of breast cancer diagnosed. This segment gave an overview of breast cancer including epidemiology, prevention, and participation in NCI breast cancer clinical trials. One clinical trial studied a woman's risk of breast cancer. Out of 1,770 women without a history of breast cancer, 72 percent accurately perceived an average risk of developing breast cancer. This study also focused on the different types of risk factors that could lead to a higher risk of developing breast cancer. Those included: sex, age, obesity, age of first menarche, and age of menopause, among others. Virtually every successful intervention for cancer treatment or prevention has been demonstrated through a clinical trial.

#### **Additional Questions and Comments from Legislators:**

- Are you seeing a difference between traditional and digital mammograms? How are insurance companies reacting? Do women gain much weight with the use of Tamoxifen? Have the side effects of Tamoxifen changed?
- Is there an advantage to taking Tamoxifen after the five years?

### **Treatment and Diagnosis of Breast Cancer: Advances and Innovation**

**Jo Anne Zujewski, MD**

Head, Breast Cancer Therapeutics  
National Cancer Institute

Genetic history and other risk factors can often affect the prognosis for breast cancer patients. Many advanced screening tools and innovation in treatments can improve the quality of life and prognosis for patients diagnosed with breast cancer. Some of these innovations include: molecular profiling, targeted therapy, clinical trial design, and targeted microenvironment. Molecular profiling early in the diagnosis of breast cancer can identify patients who may benefit from “more” or “less” therapy. In one research study, patients with tumors with high recurrence scores had strong benefits from chemotherapy, and patients with tumors with low recurrence scores had minimal, if any, benefits from chemotherapy.

#### **Additional Questions and Comments from Legislators:**

- What would it take for us to have a centralized tissue collection bank?
- Forty-seven percent of women rely on Medicaid or are uninsured in Illinois; what types of treatment are available with and without insurance?

## **Addressing Disparate Populations: Breast Cancer in Minorities**

**Anne Marie Murphy, PhD**

Director

Chicago Breast Cancer Quality Consortium

Breast cancer mortality, as compared to incidence, disproportionately affects minority groups. The disparity in breast cancer mortality in Chicago is one of the highest in the United States. Over 100 African-American women die each year in Chicago because of this inequity in mortality. Breast cancer health disparities exist nationwide; however, there appears to be significant differences in the extent of the disparity in different locations. In Chicago, African-American women are less likely to get mammograms in facilities with digital equipment, facilities that had breast imaging specialists, and they were less likely to access care in an academic facility. The Chicago Breast Cancer Quality Consortium was created to build a collaboration between providers to share quality data on access to high quality breast cancer screening and treatments.

### **Former State Senator Diana Bajoie**

Director of Community Relations, Louisiana State University Health Sciences

Center New Orleans

Breast cancer is one of the most common forms of cancer in American women. It can occur at any age, but it is more likely to occur after age 40. There are several factors that can contribute to a woman's risk of developing breast cancer, and include: personal history of breast cancer, two or more relatives with breast or ovarian cancer, inherited changes in breast cancer related genes, and previous radiation in the chest area. Some signs to watch for if a patient is concerned they may have breast cancer are a lump or thickening anywhere in the breast, skin dimpling or puckering of the breast, an inverted nipple, discharge from the nipples, and any change in shape or texture of the breast.

Race is not considered a factor that might increase a woman's chance of getting breast cancer; however, the rates of developing and dying from the disease differ among ethnic groups. The cause of this disparity may be the differences in biology of breast cancer or the differences in breast cancer screening rates and treatment. Among women under 40, African-American women have a higher incidence of breast cancer than Caucasian women. Asian women who migrate to the United States are six times more likely to develop breast cancer.

### **Additional Questions and Comments from Legislators:**

- How do you move facilities into communities with highest breast cancer mortality rates?
- There is a difference between covering screening and treatments.
- There is a disconnect between screening and diagnostic services; expensive to cover biopsies, etc. when women are uninsured.
- When we are talking about funding we should use health disparities legislation as a model; how much does this legislation cost?

**Thursday, November 5, 2009**

**State Legislation: Screening and Diagnosis**

**Representative Mary Sue McClurkin**

Chair, Women In Government Board of Directors  
Alabama State Legislature

Representative Mary Sue McClurkin discussed Alabama House Bill 147 which was enacted this year and allows for Medicaid eligibility coverage for a woman who has been screened for breast and/or cervical cancer to be determined by any healthcare provider and/or entity that receives direct payment for screening services by the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) or is partially funded by an NBCCEDP grant to provide Medicaid coverage. This determination of medical eligibility for coverage by Medicaid is to be administered by the NBCCEDP of the Alabama Department of Public Health. This legislation was enacted on April 30, 2009.

**Additional Questions and Comments from Legislators:**

- Vermont provides reduced co-pays for mammograms.
- Do women have to go to doctors that are approved under the program?
- What kind of advocates on the Senate side helped you pass this bill?

**Access to Screening: State Legislation through Coalition Building**

**Representative Peggy Welch**

Indiana State Legislature

**Patricia Ells**

Former Advocate  
American Cancer Society

Representative Peggy Welch and Patricia Ells discussed how they worked together during the 2009 legislative session to successfully eliminate insurance barriers for clinical trials, bring parity for oral chemotherapy with intravenous chemotherapy, and increase eligibility for the Breast and Cervical Cancer Screening Program. Indiana House Enrolled Act 1382 requires a state employee plan to provide coverage for routine care costs that are incurred during the course of a clinical trial if the state employee plan would provide coverage for the same routine care costs not incurred during a clinical trial. Senate Enrolled Act 554 requires the state Department of Health to change the department's Breast and Cervical Cancer Screening Program plan in a manner that will designate Indiana as an option three state, allowing a woman who is screened by other providers and entities to be identified by the state department as part of the state's insurance program. Senate Enrolled Act 437 requires coverage for orally administered cancer chemotherapy and cancer therapy that is administered intravenously or by injection.

**Additional Questions and Comments from Legislators:**

- Patients in states whose doctor has prescribed "off-label" drugs - will insurance cover this and how should legislators go about dealing with it?

## **State Legislation: Clinical Trials**

### **Senator Bettye Davis**

Member, Women In Government Board of Directors

Chair, Senate Health & Social Services Committee

Alaska State Legislature

Senator Bettye Davis discussed Alaska Senate Bill 10, which was introduced this year to ensure continued insurance coverage for cancer patients who choose to participate in clinical trials. This legislation, if enacted, would require healthcare insurers to provide insurance coverage for medical care received by a patient during certain approved clinical trials designed to test and improve prevention, diagnosis, treatment, or palliation of cancer. It would also direct the Department of Health and Social Services to provide Medicaid services to people who participate in clinical trials and to require insurance to cover certain experimental procedures under a state insurance plan offered by the Comprehensive Health Insurance Association.

### **Additional Questions and Comments from Legislators:**

- According to National Journal of Clinical Oncology, there are 200 ongoing clinical trials.
- How can we connect patients who have been diagnosed with cancer to a central database of ongoing clinical trials?
- Where could patients go to learn about how to participate in clinical trials? Patients can visit: <http://clinicaltrials.gov/>.

## **Ensuring Quality of Care: Patient Navigation Programs**

### **Senator Judy Eason McIntyre**

Oklahoma State Legislature

Cancer patients face confusion and difficulty in their battle against the disease. Senator Judy Eason McIntyre used her personal experience with breast cancer to help shape Senate Bill 434, which, if enacted, would direct the State Department of Health to provide a cancer patient navigation program which would provide education about and assistance with the management of cancer. The bill also sets minimum program guidelines, including initially serving breast and cervical cancer patients and eventually expanding to all other cancer types as the program develops, assist patients with access to healthcare, financial and legal assistance, transportation, psychological support, and other related issues as necessary, and to be a part of an existing cancer service agency, that is not affiliated with a particular healthcare institution.

## Summary of Breast Cancer Policy Workshop Breakout Sessions

### Legislation: Goals of Legislation

- Routine coverage of clinical trials care
- Navigation for cancer patients
- Medical home for adults
- Patient Navigation (Wellness Visit Prevention)
- Creating a hotline for patients to call (ex. 1-800-HOTLINE)
- ERISA- Federal legislation's impact on state screening coverage – Diagnosis not paid (ie. Biopsy, sonogram, etc.) (If mammogram shows positive- who pays for next follow-up screening?)
- Oral chemo covered same as IV chemo
- Off label drug use mandates
- Clinical trials
- Not losing insurance – do not lose standard of coverage for pre-existing conditions or after diagnosis
- High deductible insurance plans can not exclude mammograms

### Legislation: Possible Co-Sponsors

- Male legislators (spouses, mothers, grandmothers with breast cancer)
- Prostate cancer counterpart advocates
- All cancer survivors; cancer survivors who are legislators (especially from the other party)
- Healthcare Appropriation Committee members
- Other legislators within states
- Health Committee Chairs

### Legislative Allies

- State Medical Association
- Public Health Commissioners
- Medical associations
- Public Health Society
- Survivors Network especially breast and cervical cancer survivors
- American Cancer Society
- Pharmaceutical companies
- Doctors, especially primary care doctors
- Susan G. Komen Foundation
- Famous people in your state with cancer
- CEOs of communication based organizations
- Faith-based organizations
- Health departments
- Cancer coalitions

### **Legislation: Opponents**

- Financial conservatives' legislation or constituency
- Religious organizations (anti-research or medical technology)
- Some doctors
- Insurance companies

### **Legislation: Obstacles**

- Lack of funding
- Access
- Rural states (geographic)
- Lack of education and understanding for need
- Legislative time (three different committees needed for approval before action)
- Lack of available advocates
- Healthcare providers reimbursements will be cut
- Lack of leadership on issue

### **Legislation: Overcoming Opponents and Obstacles**

- Personal stories
- Third-party financial groups for health statistics
- Cost saving plans
- Educate, Educate, Educate
- Federal healthcare reform
- Women in leadership roles as sponsors
- Men as sponsors
- Bring all players to the table to discuss the issues

### **Legislation: Funding**

- Research funding
- CDC money
- State lottery ticket with breast cancer ribbon
- Private corporations
- Insurance companies

### **Non-Legislative Ideas: Goal of Project**

- Breast Cancer awareness event at the Capitol
- Creating a cancer caucus
- Colon cancer information memo to all legislators
- Other memos and information on other types of cancer and screening treatments
- CDC speakers and more information
- Improve health and access to care
- Public awareness PSAs

**Non-Legislative: Others willing to Help**

- Cancer coalitions
- Cancer survivors
- Local governments
- College health fairs

**Non-Legislative: Obstacles**

- Funding
- Fear
- Apathy

**Non-Legislative: Opponents**

- Specialist (Medical possible)
- Departments of Agency that do not want to share information

## Breast Cancer Policy Workshop

*The State Legislative Role*

November 4-5, 2009  
The Madison Hotel  
Washington, DC



## Agenda

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**Wednesday, November 4, 2009**

***Luncheon:***            ***John Adams Room***  
12:00 pm – 1:00 pm    **Welcome Lunch**

12:05 pm – 12:10 pm   Welcoming Remarks

**Mary Brooks Beatty**  
President, Women In Government

12:10 pm – 12:30 pm   Keynote Address

**Alexine Clement Jackson**  
Breast Cancer Survivor  
Susan G. Komen for the Cure Board Member

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***General Sessions:***    ***Carlton Club***  
1:00 pm – 1:45 pm    **An Overview – Breast Cancer in 2009**  
*Facilitated by: Representative Mary Sue McClurkin*  
*Chair, Women In Government Board of Directors*  
*Alabama State Legislature*

**Worta McCaskill-Stevens, MD, MS**  
Program Director, Minority-Based Community Clinical Oncology Program  
National Cancer Institute  
National Institutes of Health

The National Cancer Institute (NCI) estimates that in 2009 there will be over 194,000 new cases of breast cancer diagnosed. This segment will give an overview of breast cancer including epidemiology, prevention and participation in NCI breast cancer clinical trials.

Q & A – 10 minutes

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**General Sessions:**  
1:45 pm – 2:15 pm

**Carlton Club**

**Treatment and Diagnosis of Breast Cancer: Advances and Innovation**

*Facilitated by: Senator Karen Morgan  
Immediate Past Chair, Women In Government Board of Directors  
Utah State Legislature*

**Jo Anne Zujewski, MD**

Head, Breast Cancer Therapeutics  
National Cancer Institute

Genetic history and other risk factors can often affect the prognosis for breast cancer patients. Learn how these factors along with advanced screening tools and innovation in treatments can improve the quality of life and prognosis for patients.

Q & A – 10 minutes

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2:15 pm – 2:30 pm

**Break**

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2:30 pm – 3:30 pm

**Addressing Disparate Populations: Breast Cancer in Minorities**

*Facilitated by: Representative Kathy Hawken  
Treasurer, Women In Government Board of Directors  
North Dakota State Legislature*

**Anne Marie Murphy, PhD**

Director, Chicago Breast Cancer Quality Consortium

**Former State Senator Diana Bajoie**

Director of Community Relations, Louisiana State University Health Sciences Center  
New Orleans

Breast cancer mortality as compared to incidence disproportionately affects minority groups. This session will address policies that to address minority populations in screening, treatment, and survivorship for breast cancer.

Q & A – 10 minutes

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3:30 pm -3:35 pm

**Closing Remarks and Adjourn**

**Mary Brooks Beatty**

President, Women In Government

***Reception & Dinner: Montpelier Room***

6:30 pm – 7:00 pm     **Reception**

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7:00 pm – 8:30 pm     **Dinner**

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**Thursday, November 5, 2009**

***Breakfast: Alexander Hamilton Room***

8:30 am – 9:30 am     **Breakfast**

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***General Sessions: Montpelier Room***

9:30 am – 9:55 am     **State Legislation: Screening and Diagnosis**

*Facilitated by: Representative Kimberley Rosen  
Secretary, Women In Government Board of Directors  
Maine State Legislature*

**Representative Mary Sue McClurkin**

Chair, Women In Government Board of Directors  
Alabama State Legislature

Representative McClurkin will discuss legislation she passed in Alabama regarding Medicaid eligibility for women screened and diagnosed with breast or cervical cancer.

Q & A – 10 minutes

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**General Sessions:**  
9:55 am – 10:55 am

**Montpelier Room**

**Access to Screening: State Legislation through Coalition Building**

*Facilitated by: Representative Jo Ann Pottorff  
Member, Women In Government Board of Directors  
Kansas State Legislature*

**Representative Peggy Welch**

Indiana State Legislature

**Patricia Ells**

Former American Cancer Society Advocate

Peggy Welch and Patricia Ells worked together as a state representative and American Cancer Society Advocate, respectively, during the 2009 legislative session to successfully eliminate insurance barriers for clinical trials, bring parity for oral chemotherapy with intravenous chemotherapy, and increase eligibility for the Breast and Cervical Cancer Program. Representative Welch and Ms. Ells will share details about these bills and how they guided them through the process.

Q & A – 10 minutes

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10:55 am – 11:10 am

**Break**

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11:10 am – 11:30 am

**State Legislation: Clinical Trials**

*Facilitated by: Representative Mary Sue McClurkin  
Chair, Women In Government Board of Directors  
Alabama State Legislature*

**Senator Bettye Davis**

Member, Women In Government Board of Directors

Chair, Senate Health & Social Services Committee

Alaska State Legislature

Senator Davis will discuss legislation she introduced to ensure continued insurance coverage for cancer patients who choose to participate in clinical trials.

Q & A – 10 minutes

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**General Sessions:** **Montpelier Room**  
11:30 am – 12:00 pm **Ensuring Quality of Care: Patient Navigation Programs**  
*Facilitated by: Senator Karen Morgan*  
*Immediate Past Chair, Women In Government Board of Directors*  
*Utah State Legislature*

**Senator Judy Eason McIntyre**  
Oklahoma State Legislature

Cancer patients face confusion and difficulty in their battle against the disease. Learn how state legislation regarding patient navigation programs can improve the quality of care for all healthcare consumers.

Q & A – 10 minutes

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**Luncheon:** **Alexander Hamilton Room**  
12:00 pm – 1:00 pm **Networking Lunch**

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1:00 pm – 2:00 pm **Strategic Action Planning Session**

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2:00 pm – 2:30 pm **Report on Strategic Action Plans**

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2:30 pm – 2:35 pm **Closing Remarks and Adjourn**

**Mary Brooks Beatty**  
President, Women In Government

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## Breast Cancer Policy Workshop

*The State Legislative Role*

November 4-5, 2009  
The Madison Hotel  
Washington, DC



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**\* Denotes Speaker**

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