



**Proceedings of the
Women In Government
Fifth Annual HPV and Cervical Cancer Summit**

November 5-7, 2009
Washington, DC

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Introduction & Background

Cervical cancer is the second leading cause of cancer death in women, with almost a quarter-million deaths occurring each year. In the United States, the American Cancer Society estimates over 11,200 women will be diagnosed with and more than 4,000 women will die of cervical cancer this year. According to the Centers for Disease Control and Prevention (CDC), approximately 20 million people are currently infected with the human papilloma virus (HPV), with 6.2 million new infections occurring annually and approximately 50 percent of sexually active men and women will be infected with HPV in their lifetime. For 90 percent of infected women, the virus is naturally cleared by the body and becomes undetectable within two years. However, persistent infection with “high-risk” types of HPV can cause cell changes that, if left untreated, can lead to cervical cancer.

Women In Government (WIG), a national, bipartisan organization of women state legislators, recognizes the continuing health concern posed by cervical cancer and the unique role that legislators can play as advocates for improved access to prevention and treatment. WIG hosted our *Fifth Annual HPV and Cervical Cancer Summit – State Policy: Building a Roadmap for Legislators* that brought together state legislators and other key stakeholders to collaborate together on ideas and actions that must be taken in order to address cervical cancer as a woman’s public health issue.

The *Summit* brought together state policymakers, state agency representatives, and public health advocates - many of whom are also cervical cancer survivors - to develop strategies to overcome the numerous barriers that stand in the way of effective cervical cancer screening and treatment. Our *Fifth Annual HPV and Cervical Cancer Summit – State Policy: Building a Roadmap for Legislators* was held in Washington, DC on November 5-7, 2009 and included 21 policymakers and representatives from 14 states. The *Fifth Annual HPV and Cervical Cancer Summit* was sponsored by GlaxoSmithKline, Qiagen, Hologic, Merck and the Centers for Disease Control.

The *Fifth Annual HPV and Cervical Cancer Summit* engaged participants in discussions and strategic planning on the current landscape of cervical cancer, in addition to advances and innovations in cervical cancer screenings and treatments and what necessary steps must be taken to battle this disease.

Presentations framed important discussions on:

- State legislation and federal screening programs;
- Global Trends in HPV and cervical cancer screening;
- State legislation: state programs eliminating barriers to access and treatment, insurance coverage for HPV vaccine, and history of HPV vaccine;
- The latest information on the HPV vaccine; and
- The adolescent well visit and cervical cancer prevention.

At the conclusion of the *Fifth Annual HPV and Cervical Cancer Summit*, legislative participants were engaged in media training on vaccine safety to give legislators ideas on how to handle media inquiries on the two HPV vaccines. Participants left the *Summit* with a renewed sense of determination to improve the screening, prevention, and treatment of cervical cancer as a result of the networking and educational opportunities on other state’s legislative initiatives to combat this disease.

Summary of Sessions

Friday, November 6, 2009

National Breast and Cervical Cancer Early Detection Program

Kelley Daniel, PhD

Senior Specialist, State and Local Campaigns
American Cancer Society, Cancer Action Network

American Cancer Society's Cancer Action Network (ACS CAN) wants every American to have access to high quality breast and cervical cancer screenings, follow-up services, and treatment. The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) is administered by the Centers for Disease Control and Prevention (CDC) and offers breast and cervical cancer screenings to medically underserved women. This program provides public health screening programs in all 50 states, the District of Columbia, 4 United States territories, and 13 American Indian/Alaskan Native tribal organizations. Their focus is on low-income, uninsured, underinsured, and underserved women under the age of 65.

Some of the services provided include: clinical breast exams, mammograms, pap tests, surgical consultation, referrals to treatment, and diagnostic testing. The NBCCEDP has served more than 3.1 million women and has provided more than 7.5 million screening tests. State legislators can help support this program by increasing state funding for screening programs, support funding for the Medicaid program for cancer treatments, and contact screening and treatment programs for more state-specific information.

Additional Questions and Comments from Legislators

- We are not putting any state funds into matching accounts. What are states doing to try to keep up state matching because state funds are obviously in deficit, etc.?
- Do you have any more statistics on doctors refusing to take patients (possible statistics from 2004)?

State Legislation and Federal Screening Programs

Commander Jacqueline Miller, MD, FACS

Medical Officer, Division of Cancer Prevention and Control
Centers for Disease Control and Prevention (CDC)

Cervical cancer is the second most common female cancer worldwide. Over 500,000 new cases are diagnosed each year. Approximately 80 percent of cervical cancer cases occur in low-income countries where it is the most common form of cancer. Over 250,000 deaths are reported each year. In the United States, 11,000 new cervical cancer cases were diagnosed in 2005 and 3,924 women died from this disease. Cervical cancer incidence and mortality rates are higher among poor women regardless of race. Women living below the poverty line were also more likely to be HPV positive compared to women who lived at three times or more above the poverty line.

Some of the risks for cervical cancer include: persistence of HPV, sexual partners, cigarette smoking, oral contraceptives, and rarely or never having been screened for the disease. There are 15 types of HPV related cervical cancer. Most abnormal pap smears are due to the presence of HPV. Nearly 70 percent of diagnosed cases of cervical cancer were caused by types 16 and 18. Incidence and mortality from cervical cancer has decreased over 75 percent since the introduction of the pap test, however 50 percent of all cervical cancer cases are among women who have never been screened.

An Overview of HPV and Cervical Cancer: The Future of Prevention, Early Detection and Treatment

Lisa Flowers, MD

Associate Professor, Obstetrics and Gynecology
Emory University

Approximately 20 million people in the United States are currently infected with HPV. It is the most common sexually transmitted infection with an annual incidence report of 6.2 million. Over \$1.6 billion dollars are spent on direct medical costs of HPV. An estimated 75 percent of sexually active people will be exposed to HPV in their lifetime. The HPV vaccine offers many benefits to preventing this infection. The HPV vaccine can help reduce the incidents of cervical cancer and genital warts. More than 16 million doses of the HPV vaccine have been delivered since 2006. The recommended target age of girls who should receive this vaccine is 11 to 12 years of age. In addition to vaccination, regular pap smears are essential to preventing cervical cancer.

Additional Questions and Comments from Legislators

- If girls are having sex at younger ages, should the recommended age of 30 for administering the HPV test be reduced?
- We have to show African-American women that we care about them; they need to come back to check their abnormal pap smears.
- Why is HPV not treated as an immune disorder? Do younger women have a better immune system?

HPV and Cervical Cancer Screening: Global Trends

Philip Castle, PhD, MPH

Investigator, National Cancer Institute

We can drastically reduce the incidence, morbidity, and mortality due to cervical cancer. However, it is highly unlikely that we can completely eliminate cervical cancer. Attempts to do so will result in escalating costs with little or no benefit to women. Understanding the natural history of any disease can and should guide the best use of an intervention. Cervical cancer prevention should be the crowning example and the flag ship of smart medicine.

Additional Questions and Comments from Legislators

- Now that we are vaccinating boys, will this make the controversy around the vaccine any different?
- Are there quantitative studies done on boys yet?
- How do we make prevention more efficient? How do we get it passed in our legislatures?
- How will healthcare reform help us with HPV screening, prevention, death rates, etc.? Will healthcare reform help with reimbursements for screening?
- If other countries that have less spending and better outcomes, what are they doing that we are not?
- As legislators begin talking about 2010 and 2011 budgets, most conversations were about diabetes and nutrition; what role do you think the allocation of money is going to play?
- Do you think HPV vaccination is the next thing to be misused because of reimbursement policies?

What's New with the HPV Vaccine

Melinda Wharton, MD, MPH

Captain, United States Public Health Service

Acting Director, National Center for Immunization and Respiratory Diseases
Centers for Disease Control and Prevention (CDC)

New recommendations have been made by the CDC's Advisory Committee on Immunization Practices to now allow for the HPV vaccine to be administered to males. Men have a similar prevalence of HPV infection compared to their female counterparts. The burden of diseases and cancers in men include: genital warts, recurrent respiratory papillomatosis, anal, penile, oral cavity and oropharyngeal cancers. Use of the HPV vaccine is approved for males aged nine to 26 years of age. The vaccine is currently recommended for males to help reduce the likelihood of acquiring genital warts.

The Adolescent Well Visit and Cervical Cancer Prevention

Kirsten Hawkins, MD, MPH, FAAP

Assistant Professor, Department of Pediatrics, Adolescent Medicine
Georgetown University Hospital

Representative Patricia Bellock

Midwestern Regional Director, Women In Government Board of Directors
Illinois General Assembly

Adolescent well visits during the teen years are important for preventive services such as vaccines, as well as education about the health effects of risky behaviors. Some young people, mostly those that are uninsured or underinsured, have little to no access to mainstream primary care services. They are more likely to rely on emergency rooms for routine care. The American Academy of Pediatrics recommends annual well visits from ages 11-21. Teens typically wait approximately two years after their first sexual activity to visit a physician's office. A major concern to teens is a lack of confidentiality and nearly half of all sexually active teens stated they would stop seeking health services if their parents were notified. Teens should be encouraged to live healthy lifestyles by instilling healthy dietary habits, regular exercise, responsible sexual behaviors and avoidance of tobacco, alcohol, and other illegal substances.

Additional Questions and Comments from Legislators

- Confidentiality - offer texts, emails, or ways for adolescents to be contacted without parents finding out.
- What kind of reaction did you get to your adolescent wellness program? What is your ultimate goal?
- Are you mandating counseling? What age?

State Programs Eliminating Barriers to Access and Treatment
Former State Representative Denise Barnard
Vermont State Legislature

Allison Hicks

President and Founder, The Hicks Foundation
Cervical Cancer Survivor

Former State Representative Denise Barnard and Allison Hicks discussed Vermont House Bill 715 that created the Vermont Cervical Cancer Eradication Task Force. The Task Force considers public awareness of the causes of cervical cancer, personal risk factors, the value of prevention and early detection, options for testing, treatment costs and health plan reimbursements, and new technologies. In addition, the Task Force must recommend testing protocols and schedule cervical cancer screenings and treatment programs, issues of cost and insurance and health plan coverage, and potential sources of funding for education, screening, and treatment programs, including government and private funding. The Task Force is also required to present recommendations to the Commissioner of Health and provide recommendations for what actions the Department of Health can implement and what recommendations require legislative action.

Additional Questions and Comments from Legislators

- What did you receive the \$2 million for specifically?
- Do you know the percentage of girls that are getting vaccinated now?

State Legislation: Insurance Coverage for HPV Vaccine
Senator Diane Rosenbaum
Oregon State Legislature

Senator Diane Rosenbaum discussed Oregon House Bill 2794, which was recently signed into law and requires all health benefit plans to provide insurance coverage of the human papilloma virus vaccine for all female beneficiaries who are at least 11 years of age, but no older than 26 years of age.

Additional Questions and Comments from Legislators

- Can we have a link to your legislation?

State Legislation: History of HPV Vaccine Legislation in Minnesota
Senator Sharon Erickson Ropes
Minnesota State Legislature

Amy Brenengen
Director, Office on the Economic Status of Women
Minnesota State Legislature

Senator Sharon Erickson Ropes and Amy Brenengen discussed the history of the HPV vaccine legislation in Minnesota and the collaborative efforts between the legislature and the Office on the Economic Status of Women and lessons learned. In 2005 and 2006, a Cervical Cancer Elimination Task Force was created. In 2007, a cervical cancer/HPV vaccine study bill passed as part of the Omnibus Health and Human Services bill. The study did not recommend the vaccination and concluded more time was needed for the public to study and accept the vaccine, for providers to have the ability to offer to the vaccine to patients, and funding streams needed to be more dependable and consistent. In 2008, an HPV vaccine information requirement bill was introduced to significant opposition. In 2009, an HPV information website was launched for constituents to have access to vaccine information. In the future, Minnesota hopes to reinvigorate the Cervical Cancer Task Force, emphasize education to the public on the benefits of the vaccine, and to use the recent approval of a vaccine for boys/men to continue the conversation.

Saturday, November 7, 2009

MEDIA TRAINING — HPV VACCINE SAFETY

Tanya Johnson, MPH

Health Communication Specialist, Division of Healthcare Quality Promotion, The National Center for Preparedness, Detection, and Control of Infectious Diseases, Centers for Disease Control and Prevention (CDC)

Susan Maguire, MA, MSW

Senior Communications Advisor, The Academy for Educational Development

Elizabeth Ryan, MPH

Senior Communication Program Manager, The Academy for Educational Development

During the media training, legislators were provided with background information on how vaccines are treated pre-licensure and post-licensure. There are two types of vaccines for HPV, Gardasil and Cervarix, which are recommended for girls between the ages of 11-12 years of age. There are several evaluation systems used track vaccine safety. The Vaccine Safety Events Reporting System (VAERS) is designed to identify potential adverse events that need additional study. The Brighton Collaboration is an international system and develops and evaluates globally accepted standards on vaccine safety.

In addition to this background information, legislators were provided with guidelines on how to conduct themselves during media interviews on vaccine safety. Legislators should determine key messages and identify clear and concise points to reinforce perceptions and dispel misperceptions of HPV vaccines. Their message should be supported with facts and statistics. Legislators were also told to be prepared for some easy questions and tough questions related to HPV vaccine safety. The most important part of an interview is body language and using talking points to turn negative or neutral questions into positives.

Additional Questions and Comments from Legislators

- What is the difference between Gardasil and Cervarix?
- How diverse is the population that you test vaccines on - geography, race, etc?
- Did studies in five continents to ensure diverse ethnicity pay attention to representation of different groups?
- Some critics of the vaccine thought that making this information available would encourage sex at a younger age - any thoughts on that?
- The increase in teen sex argument is illogical; would you not tell your child to wear a seatbelt because it encourages reckless driving?
- WIG received letters from a campaign that said their daughters went into seizures after taking the vaccine - can you comment on that?
- How are genital warts treated if a man/woman does not have the vaccine? Are we talking about a sexually transmitted infection that can turn into cancer?
- It is important to get messages of responsibility from parents.
- What other things are in the vaccine besides just the portion for the vaccine itself?
- Parents need to talk to kids, but they also need to be educated as well on the vaccines.

Fifth Annual HPV and Cervical Cancer Summit

State Policy: Building a Roadmap for Legislators

November 5-7, 2009

The Madison Hotel

Washington, DC



Agenda

Thursday, November 5, 2009

Reception & Dinner: Mt. Vernon Salon A

6:30 pm – 7:00 pm **Opening Reception**

7:00 pm – 8:30 pm **Dinner**

7:00 pm – 7:05 pm Welcoming Remarks

Mary Brooks Beatty
President, Women In Government

7:05 pm – 7:25 pm Keynote Address

Congresswoman Debbie Halvorson
United States Congress

Friday, November 6, 2009

Breakfast: ***Mount Vernon Room***

8:00 am – 9:00 am **Breakfast**

General Sessions: ***Dolley Madison Ballroom***

9:00 am – 9:05 am **Welcoming Remarks**

Mary Brooks Beatty
President, Women In Government

Friday, November 6, 2009

General Sessions: Dolley Madison Ballroom

9:05 am – 9:45 am ***NATIONAL BREAST AND CERVICAL CANCER EARLY DETECTION***

PROGRAM

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

Kelley Daniel, PhD

Senior Specialist, State and Local Campaigns
American Cancer Society, Cancer Action Network

This segment will focus on a CDC program which provides access to breast and cervical cancer screening services to underserved women.

9:45 am - 10:30 am **State Legislation and Federal Screening Programs**

*Facilitated by: Senator Katie Dorsett
Vice Chair, Women In Government Board of Directors
North Carolina State Legislature*

Commander Jacqueline Miller, MD, FACS

Medical Officer, Division of Cancer Prevention and Control
Centers for Disease Control and Prevention (CDC)

Delegate Margaret Vanderhye

Virginia State Legislature

State legislation which increases services consistent with CDC programs will be discussed.

Friday, November 6, 2009

General Sessions: *Dolley Madison Ballroom*

10:30 am – 11:00 am **An Overview of HPV and Cervical Cancer: The Future of Prevention, Early Detection and Treatment**

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

Lisa Flowers, MD

Associate Professor, Obstetrics and Gynecology
Emory University

This segment will address the current landscape of HPV and cervical cancer prevention and treatment, recent developments, as well as the future of the disease.

Q & A – 10 minutes

11:00 am – 11:15 am **Break**

11:15 am – 11:55 am **HPV and Cervical Cancer Screening: Global Trends**

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

Philip Castle, PhD, MPH

Investigator, National Cancer Institute

Learn how the natural history of the human papillomavirus dictates the best (age-appropriate) use of prevention strategies. Also discussed will be the role of screening in the prevention of cervical cancer now and in the future in the United States and abroad.

Q & A – 10 minutes

Friday, November 6, 2009

General Sessions: *Dolley Madison Ballroom*

11:55 am – 12:40 pm **What's New with the HPV Vaccine**

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

Melinda Wharton, MD, MPH

Captain, United States Public Health Service
Acting Director, National Center for Immunization and Respiratory Diseases
Centers for Disease Control and Prevention (CDC)

This session will focus on recent recommendations made by CDC's Advisory Committee on Immunization Practices regarding the new HPV vaccine and HPV vaccination for males. The latest data on teen immunization rates from the National Immunization Survey will also be presented.

Q & A – 10 minutes

Luncheon: *Mount Vernon Room*

12:40 pm – 1:40 pm **Networking Lunch**

1:40 pm – 2:40 pm **The Adolescent Well Visit and Cervical Cancer Prevention**

*Facilitated by: Senator Bettye Davis
 Member, Women In Government Board of Directors
 Alaska State Legislature*

Kirsten Hawkins, MD, MPH, FAAP

Assistant Professor, Department of Pediatrics, Adolescent Medicine
Georgetown University Hospital

Representative Patricia Bellock

Midwestern Regional Director, Women In Government Board of Directors
Illinois General Assembly

Well visits during the teen years are important for preventive services such as vaccines, as well as education about the health effects of risky behaviors. We will hear about the role policymakers play in ensuring teens see primary care providers regularly, and the influences these and other caring adults can have on youth well-being.

Q & A – 10 minutes

Friday, November 6, 2009

General Sessions: *Dolley Madison Ballroom*

2:40 pm – 3:25 pm **State Programs Eliminating Barriers to Access and Treatment**

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

Former State Representative Denise Barnard

Vermont State Legislature

Allison Hicks

President and Founder, The Hicks Foundation

Cervical Cancer Survivor

Former State Representative Denise Barnard and Allison Hicks will present on legislation that was passed in Vermont as well as work that has been done on the Vermont Cervical Cancer Task Force.

Q & A – 10 minutes

3:25 pm – 3:45 pm **State Legislation: Insurance Coverage for HPV Vaccine**

*Facilitated by: Representative Patricia Bellock
Midwestern Regional Director
Women In Government Board of Directors
Illinois State Legislature*

Senator Diane Rosenbaum

Oregon State Legislature

This segment will address legislation in Oregon that was recently signed into law that requires insurance coverage of the HPV vaccine for females who are at least 11 years of age, but no older than 26 years of age.

Q & A – 10 minutes

Friday, November 6, 2009

General Sessions: Dolley Madison Ballroom

3:45 pm – 4:15 pm **State Legislation: History of HPV Vaccine Legislation in Minnesota**

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

Senator Sharon Erickson Ropes

Minnesota State Legislature

Amy Brenengen

Director, Office on the Economic Status of Women

Minnesota State Legislature

This segment will cover the history of HPV vaccine legislation in Minnesota and the collaborative efforts between the legislature and the Office on the Economic Status of Women and lessons learned.

Q & A – 10 minutes

4:15 pm

Adjourn

6:15 pm

Meet in Lobby to Depart for Dinner

6:30 pm – 8:30 pm

Dinner and Presidential Leadership Awards Ceremony at Daughters of the American Revolution National Society O'Byrne Gallery

Saturday, November 7, 2009

Breakfast: Mount Vernon Room

8:30 am – 9:30 am **Breakfast**

Media Training: Dolley Madison Ballroom

Mock Interviews: Dolley Madison Ballroom & Montpelier Room

9:30 am – 12:30 pm **MEDIA TRAINING — HPV VACCINE SAFETY**

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

Tanya Johnson, MPH

Health Communication Specialist, Division of Healthcare Quality Promotion, The National Center for Preparedness, Detection, and Control of Infectious Diseases, Centers for Disease Control and Prevention (CDC)

Susan Maguire, MA, MSW

Senior Communications Advisor, The Academy for Educational Development

Elizabeth Ryan, MPH

Senior Communication Program Manager, The Academy for Educational Development

9:30 am – 10:15 am Vaccine Safety Basics and Update on HPV Vaccine Safety

10:15 am – 10:30 am Questions and Answers

10:30 am – 11:00 am Key Messages about HPV Vaccine Safety and Tips for Giving a Good Interview

11:00 am – 11:15 am Break

11:15 am – 12:15pm Optional Mock Interview Practice and Feedback

12:15 pm – 12:30 pm **Wrap Up & Adjourn**

Mary Brooks Beatty

President, Women In Government

Appendix B Participant List

Fifth Annual HPV and Cervical Cancer Summit

State Policy: Building a Roadmap for Legislators

November 5-7, 2009
The Madison Hotel
Washington, DC



Participant List

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