



Prevention Connection

On the Cutting Edge of Cervical Cancer Policy

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WOMEN IN GOVERNMENT to host the first-ever HPV and Cervical Cancer Summit

From the Pap test to public information campaigns, cervical cancer knowledge and technology have come a long way in recent decades. Since the 1950s, the incidence of cervical cancer in the United States has decreased steadily. Thanks to advancements in treatment and detection of the disease, and increased public awareness about women's health, cervical cancer is preventable with regular and appropriate screening.

In 2004, Women In Government members recognized that the preventability of cervical cancer presented a unique public policy opportunity to score the first "win" in the fight against cancer. The *Challenge to Eliminate Cervical Cancer Campaign* was the result of Women In Government's commitment to eliminating cervical cancer through sound public policy and public health initiatives.

Now, nearly two years after the Campaign was launched, cervical cancer as a policy issue continues to gain momentum. To date, 33 states have enacted cervical cancer prevention and education bills or resolutions, and 42 states have introduced such legislation. To build on the legislative successes and to broaden the reach of the issue, Women In Government is hosting the first-ever HPV and Cervical Cancer Summit.

The summit, to be held in Atlanta on November 17-19th, will bring together policymakers, representatives from the Centers for Disease Control and Prevention, physicians, public health officials, and women's health advocates to discuss all facets of the fight against cervical cancer.

"Women In Government will provide summit participants with the most comprehensive, up-to-date cervical cancer knowledge available," said Susan Crosby, Executive Director and President of Women In Government. "We are excited to explore new policy solutions and emerging technologies that further the goals of the *Challenge to Eliminate Cervical Cancer Campaign*."

The Summit will include segments on advanced technologies in cervical cancer screening and prevention, international cervical cancer prevention efforts, and the importance of public information efforts that encourage women to receive regular and appropriate screening. Each segment will highlight the most current available research on the topic and feature speakers who are leaders in their fields.

Racial disparities in cervical cancer incidence will also be among Summit topics. A recent report by the National Cancer Institute's Center to Reduce Cancer Health Disparities concludes that cervical cancer mortality is highest among African American women in the South, Latina women in the Texas-Mexico border, white women in Appalachia, American Indians of the Northern Plains, Vietnamese American women, and Alaska natives. The National Cancer Institute recommends improvements in research, communications, and outreach to reduce cervical cancer disparities, and urges the federal government to develop health initiatives geared specifically toward certain high-risk populations.

The Summit will also cover patient/provider communication and education,

based on the findings of a survey conducted by the Association of Reproductive Health Professionals. The survey assessed patient and healthcare provider attitudes and perceptions about cervical cancer and its cause, the Humanpapillomavirus (HPV). The conclusion – that women and their doctors are not communicating about a preventable disease – underscores the need for women to be actively involved in their health care and for doctors to educate patients on the link between HPV and cervical cancer.

Additionally, the Summit will provide an opportunity for participants to engage in small-group discussions about state and regional prevention and education initiatives.

On Friday night, summit participants will have the opportunity to attend a concert by cervical cancer survivor and musician Christine Baze. Baze's battle with the disease prompted her to found PopSmear.org, a Boston based non-profit organization that raises awareness and money to fight cervical cancer. The organization recruits help from musicians in Boston and around the country to perform benefit concerts for HPV and cervical cancer research.

This year's summit serves as both mile marker and a starting point in the next phase of the *Challenge to Eliminate Cervical Cancer Campaign*; it represents a significant increase in awareness and concern about cervical cancer, and also a foundation for future coordinated policy and community action. For more information about the Summit, please contact the Women In Government HPV and Cervical Cancer Policy Resource Center at (888) 333-0164 or resourcecenter@womeningovernment.org. ■

JOHANNA'S LAW: WORKING TOGETHER TO EDUCATE WOMEN ABOUT GYNECOLOGIC CANCERS

By Sheryl Silver, founder and president
Johanna's Law Alliance for Women's Cancer Awareness

Johanna's Law: *The Gynecologic Cancer Education and Awareness Act*

aims to improve early detection of gynecologic cancers by creating a federal education campaign to inform women about the risk factors and symptoms of ovarian, cervical, and other gynecologic cancers. Armed with these facts, women can more easily recognize dangerous symptoms, seek appropriate medical attention quickly, and ask questions to ensure gynecologic cancers are considered among the possible causes of their symptoms early in the assessment process not months later, as so often occurs.

I first conceived of Johanna's Law in August of 2002. When I saw Representative Sander Levin (D-MI) at an event a few weeks later, I asked him if he would sponsor the bill. My sister Johanna, who died from ovarian cancer, had taught high school in Mr. Levin's district.

In making a case for the bill, I explained that a pervasive lack of knowledge about ovarian cancer symptoms commonly led to lengthy — and often lethal — delays in diagnosis of the disease. The divide between what women know about gynecologic health and what women need to know to live healthy lives means that too many women, including my health-conscious sister Johanna, are falling victim to a life-threatening information gap.

Johanna lost precious time taking antacids, then waiting several weeks to see a gastroenterologist for what she thought were symptoms of a minor gastric problem. By the time she saw her gynecologist and the right diagnostic studies were performed, Johanna was immediately scheduled for surgery. That surgery confirmed she had a late stage of ovarian cancer. She was given 12-18 months to live. Four surgeries and aggressive chemotherapy regimens allowed Johanna to survive three and a half years.

During the course of Johanna's illness and treatment, I realized how tragically common her experience was. Almost every woman I met at support groups and national conferences had been diagnosed with ovarian cancer at late stages of the disease and learned only AFTER being diagnosed that the symptoms they had experienced for months were common to ovarian cancer. Almost all of their doctors had attributed their early symptoms to benign conditions and because these women didn't know their symptoms could indicate ovarian cancer, they weren't even able to ask their doctors: "Shouldn't

we first rule out ovarian cancer, the deadliest cause of these symptoms, before assuming something benign is the underlying problem?" Johanna's Law addresses this tragic status quo by educating women about the symptoms of ovarian and other gynecologic cancers.

September is Gynecologic Cancer Awareness Month

Mr. Levin ultimately agreed to author Johanna's Law. Representative Kay Granger (R-TX) soon joined him as the bill's Republican sponsor. The Society of Gynecologic Oncologists (SGO) and the Gynecologic Cancer Foundation (GCF) were quick to endorse the bill. SGO then helped garner endorsements from other groups including the American College of Obstetricians and Gynecologists, National Ovarian Cancer Coalition, and Ovarian Cancer National Alliance.

Johanna's Law was introduced on November 4, 2003 and due largely to advocacy efforts by members of its supporting groups, had 144 co-sponsors by the time the 108th Congress adjourned. Since the bill was not acted upon before adjournment, it was reintroduced this year as H.R. 1245 by Representatives Darrell Issa (R-CA),

Rosa DeLauro (D-CN), Kay Granger and Sander Levin and over 80 original co-sponsors. Due to continued advocacy efforts, today Johanna's Law has bipartisan co-sponsorship from 227 United States Representatives. The Senate companion bill, S. 1172, introduced in June 2005 by Arlen Specter (R-PA) and Tom Harkin (D-IA), has 25 co-sponsors.

Hearings that focused on the need for Johanna's Law and a national program of gynecologic cancer education were held on May 11th by the Senate Labor Health & Human Services and Education Subcommittee and on September 7th by the House Subcommittee on Criminal Justice, Drug Policy and Human Resources.

Our next goal in the effort to pass Johanna's Law is to quickly and substantially increase the number of Senate co-sponsors for S. 1172 while adding more co-sponsors in the House.

For more information about Johanna's Law, visit www.johannaslaw.org or the SGO Web site: www.sgo.org

Women In Government is proud to support Johanna's Law and the prevention, education and early detection of gynecologic cancers. ■



A CONVERSATION WITH DR. MARIE SAVARD

How can policymakers work with the medical community to address the issue of cervical cancer? How can each reach out to the other in order to create sound public policy?

In order to develop sound public policy, policymakers can:

- Work with medical organizations, such as the American Cancer Society, to identify current needs and practices.
- Identify which ob/gyns, pathologists, internists, pediatricians, etc. in their areas are the top researchers and thought leaders on this issue. Ask these specialists for information about new clinical research and its implications – both currently and in the future. To identify these medical experts, ask local health reporters for local university clinicians who are quoted in news articles, or ask the American Cancer Society for local contacts.

In order to help drive and support effective public policy, interested physicians should:

- Meet with their local legislators to bring them up to speed on the latest clinical data and its implications for constituents. Highlight the public needs that they have identified through their own practices and through networking with other physicians.
- Stay in touch by providing lawmakers with updates, new studies, patient feedback and concerns.

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What sort of public health policy is most effective?

The most effective public health policy is that which is developed with input from all elements of the healthcare delivery system. Good public health policy can be formulated with attention to:

- A broad, but appropriate range of physicians (primary care and ob/gyns, etc.)
- Public health providers (public health department, subsidized clinics, HMOs, etc.)
 - Medicaid population
 - Insurance industry
 - Pharma/diagnostics
 - Patient/advocacy community
- If regulations are being changed – such as insurance requirements to reimburse for advanced technologies – public and physician education should be part of the equation. Education should encompass understanding the disease, as well as the new and developing techniques and treatments involved (e.g., the HPV test and HPV vaccine). Physicians should also be made aware of the new legislation itself.

How can policymakers best use physicians' knowledge?

Use physicians as resources to glean the latest clinical data.

Talk to physicians in different practice settings to understand what their opportunities and challenges are in improving cervical cancer screening and prevention.

Ask physicians to testify during hearings, speak to the media and constituent groups, and provide materials for the public.

Physicians may also be able to provide representative patients, such as cervical cancer survivors, who might be willing to share their experiences as part of hearings, media events, and women's group meetings.

Who are some of the key physician groups that policymakers should partner with in their cervical cancer advocacy efforts?

This will likely vary from region to region, but in general the following groups have state organizations:

- American Cancer Society
- American College of Obstetricians and Gynecologists

Dr. Savard is a nationally-known internist, women's health expert and patient advocate.

ARIZONA'S CONTINUED EFFORTS TO EDUCATE WOMEN AND PREVENT CERVICAL CANCER

by Representative Linda Lopez

Passing legislation – even when it has the potential to save lives – can be challenging. Last session, I carried House Bill 2615, which would have created a Cervical Cancer Study Committee in Arizona. The Arizona Cervical Cancer Study Committee was to be comprised of legislators, public health officials, women's health advocates, and physicians. The group was charged with assessing Arizona's cervical cancer disease burden. My aim in establishing a state study committee was to determine how Arizona can improve women's health by ensuring that all women have access to regular and appropriate screening for cervical cancer. The Arizona Cervical Cancer Study Committee would have been very similar to committees that have been operating in numerous other states.



Unfortunately, this bill did not pass even though every woman – and most of the men – in the Arizona legislature signed on to the bill. House Bill 2615 sailed out of the House and through the Senate Health committee, but was blocked in the Senate Rules Committee.

Study committees can be extremely beneficial to policy makers because they allow a small group of individuals to take a close look at an issue, and make educated policy recommendations based on their examination. A study committee can also be controversial and unpopular because of the issue it addresses, and the funding – however minimal – it requires. Needless to say I was very disappointed that the Cervical Cancer Study Committee failed to materialize.

However, all is not lost. I am continuing to pursue the study committee through another avenue. Along with other women legislators in Arizona, I am asking the President of the Senate and the Speaker of the House to establish an ad hoc interim committee to study this issue. This issue is incredibly important to all women in Arizona, and particularly to our large Hispanic population. According to Dr. Francisco Garcia at the University of Arizona in Tucson minority women, including Hispanic women, are much more at-risk for cervical cancer than other women.

As you all know, the key to success in the legislature is perseverance. If at first you don't succeed, try, try again! Stay tuned as I continue to pursue this issue with the support of my colleagues in Arizona.

Representative Lopez can be reached at llopez@azleg.state.az.us or (602) 926-4089. ■

MARYLAND'S ACTIONS TO REDUCE CERVICAL CANCER INCIDENCE

by Sen. Gloria Lawlah

Each year, five out of every 1,000 Marylanders will develop cancer, according to the Maryland Department of Health and Mental Hygiene. Cervical cancer is among the diseases that affect Marylanders; however, unlike some cancers, cervical cancer can be prevented with regular and appropriate screening. Given the preventability of cervical cancer, public policy that improves education and detection efforts can significantly reduce the disease burden on women.



In each of the past two legislative sessions, I have made cervical cancer prevention a top priority. In 2004, I sponsored Senate Bill 499, which established a Cervical Cancer Committee within the Maryland Comprehensive Cancer Control Plan. The committee is charged with promoting public awareness about the causes and nature of cervical cancer, risk factors, testing options, treatment costs, the value of prevention, and with evaluating the efficacy of existing programs, services, laws and regulations. The committee is required to present its findings and recommendations to the Governor and the General Assembly annually for five years.

In addition to promoting public education, the committee develops a statewide Cervical Cancer Prevention Plan and strategies for plan implementation and public promotion, while facilitating communication between state and local agencies about the plan.

Finally, the bill requires the committee to examine insurance coverage and reimbursement for cervical cancer detection and treatment. The insurance component of Senate Bill 499 led me to sponsor Senate Bill 779 this past session.

Senate Bill 779 requires specific insurers, nonprofit health service plans, and health maintenance organizations to provide coverage for the human papillomavirus screening test at

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intervals recommended by the American College of Obstetricians and Gynecologists. The human papillomavirus is recognized by physicians as the most common cause of cervical cancer, and in 2003 the Food and Drug Administration approved a test for HPV that, when used in conjunction with the Pap test, can more accurately predict future incidence of cervical cancer in some women.

Maryland's cancer death rate is the sixth highest in the United States. Cervical cancer is almost entirely preventable, and should not be among Maryland's cancer killers. The legislation I sponsored is part of a state and nationwide effort to prevent unnecessary women's death. I look forward to witnessing the future impact of these efforts.

Senator Gloria Lawlah can be contacted at gloria_gary_lawlah@senate.state.md.us or at (410) 841-3092 or (301) 858-3410. ■

IN THE NEWS

EUROGIN

The European Research Organization on Genital Infection and Neoplasia (EUROGIN) has invited Susan Crosby, President and Executive Director of Women In Government, to speak at their 2006 meeting in Paris next Spring. EUROGIN 2006 will focus entirely on global infection rates of human papillomavirus as well as worldwide cervical cancer prevention efforts. Topics to be addressed include emerging screening technologies, vaccinations,

and efforts to reduce the rate of HPV in developing countries. Women In Government is honored to have been chosen to participate, and is in the process of determining how we can make this experience most valuable to our members.

WIG and WNBA

Women In Government (WIG) and the Women's National Basketball Association (WNBA) share a mutual interest in educating women about cervical cancer. Last month, WIG and the WNBA teamed up with several other organizations at a New York Liberty basketball game to urge women over 30 to "Choose to Know" their HPV status. The event, featuring musician and cervical cancer survivor Christine Baze, was a huge success.

CDC Study Evaluates Impact on Screening Rates of Physician Recommendations

A recent CDC study found that while many women in the United States undergo routine cervical cancer screening, some women have rarely or never had a Pap test.

Research on other cancer screening tests such as mammograms has shown that a physician recommendation to get a screening test is one of the strongest predictors of patient cancer screening. Using data from the 2000 National Health Interview Survey, the study examined whether women in the U.S. had received a physician recommendation

to get a Pap test. The study also looked into reported reasons for not receiving a Pap test. The findings suggest that lack of physician recommendation contributes to underuse of Pap screening by many eligible women. Given research that shows the effectiveness of physician recommendations in improving use, increased physician recommendations could contribute significantly to increased Pap screening use in the United States.

CHALLENGE TO ELIMINATE CERVICAL CANCER CAMPAIGN UPDATE

Last month, New York became the thirty-third state to enact legislation pertaining to cervical cancer education and prevention. With 33 states enacting legislation, and a total of 42 states introducing legislation, the *Challenge to Eliminate Cervical Cancer Campaign* continues to garner attention and generate momentum.

In the coming months, the Campaign will be focused on the November HPV and Cervical Cancer Summit and the 2006 State Report, due out in January. The 2006 State Report will reflect campaign developments, as well as suggest additional areas where states can improve.

For more information on the *Challenge to Eliminate Cervical Cancer Campaign*, please visit www.womeningovernment.org/prevention

WIG is a national 501(c)(3), non-profit, bi-partisan organization of women state legislators providing leadership opportunities, networking, expert forums, and educational resources to address and resolve complex public policy issues.

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