



HPV & CERVICAL CANCER PREVENTION 2009 INTERNATIONAL TOOLKIT

THE CHALLENGE TO ELIMINATE CERVICAL CANCER: A CAMPAIGN NARRATIVE

INTRODUCTION

Women In Government (WIG) established the Challenge to Eliminate Cervical Cancer Campaign in 2003. Since the Campaign began, all 50 states have passed legislation aimed at eliminating cervical cancer and WIG has become a leader in promoting policies that help reduce the burden of cervical cancer. WIG utilized a variety of approaches including the state cervical cancer task forces, educational campaigns, policies to promote early detection programs, and policies on compulsory human papillomavirus (HPV) vaccine and testing insurance reimbursements.

For over 20 years, WIG, a nonprofit/non-governmental, educational association for U.S. women state policymakers, has developed programs focusing on cutting edge policy issues in America. The public policy issues WIG tackles are determined in part by our Board of Directors, general legislative membership, and staff. The majority of our members serve on education and/or health committees in their states which are tasked with guiding and developing legislation in these areas that will be considered by the entire legislature. Our organization provides important professional development opportunities for policymakers, while also identifying and recommending solutions where there are gaps in public policy.

This document details the development, strategies, successes and challenges of WIG's landmark policy campaign: the Challenge to Eliminate Cervical Cancer. The goals of this program are (1) to educate legislators and their constituents about this preventable disease through evidence-based information and (2) to partner with legislators and other stakeholders to advance cervical cancer prevention policies. WIG believes that the lessons learned from this Campaign could be a starting point for other U.S. policy initiatives, and potentially provide ideas to policymakers and advocates in other countries. WIG aims to move the Campaign into the global arena given that other parts of the world – particularly developing countries – carry a much larger disease burden from cervical cancer and have a significantly higher fatality rate from the disease. WIG recognizes that health systems, the role of government, cultural norms and funding resources vary greatly from country to country. Thus, WIG presents these materials as a set of tools for policymakers and others to use in building political will and garnering support for cervical cancer prevention efforts. WIG does not expect that there will be a “one size fits all” strategy.

This document is separated into sections based on the different phases of our Campaign. It provides a narrative with details on the activities in that time, followed by a box summarizing suggestions and lessons learned.

PHASE ONE: EDUCATION

In 1900, cervical cancer was the leading cause of cancer death for American women. In 1943, the development of the Pap test by Dr. George Papanicolaou of Cornell University was acknowledged, and as a result, the history of cervical cancer changed dramatically. By screening women for abnormal cervical cells on an annual basis, healthcare providers were able to identify and remove precancerous lesions before they become dangerous. With this new diagnostic tool, the number of women being diagnosed and dying from cervical cancer in the U.S. and many industrialized countries significantly declined.

In the 1970s, a new story for cervical cancer emerged with the discovery that HPV is the primary cause of the disease. This discovery changed the landscape of cervical cancer prevention – and public policy too. Armed with additional information about the virus and an understanding about the connection between HPV and cervical cancer, the public and private sector began working on new medical marvels and public policies that would take us a step further in preventing this disease.

The HPV test, a new technology released in 2002, further developed screening options for detecting active HPV infection. In the same year, WIG reached out to our membership to determine whether they wanted WIG to increase our cervical cancer prevention efforts. In January 2003, WIG held our very first session on cervical cancer and its causes at our Annual State Directors Conference for a group of approximately 40 policymakers.

First Steps in the Campaign

Early on, WIG teamed up with North Carolina Senator Virginia Foxx to conduct an educational briefing for other legislators. Senator Foxx's leadership and her commitment to cervical cancer prevention helped the issue gain momentum and led legislators in other states to act. In spring of that same year, WIG formed an HPV and Cervical Cancer Task Force. The goal for the Task Force, a bipartisan group of legislators, physicians, and leaders in cervical cancer advocacy, is to identify gaps in cervical cancer policy and to develop strategies to close those gaps. The group also determined that they wanted to stimulate a national discussion about this disease, educate and communicate with the public, develop an action or best practice plan for prevention, and provide accessible, easy to use resources for other policymakers. We took our educational program to numerous meetings, including the annual Regional Conferences. In that time span, WIG provided basic cervical cancer education to over 130 policymakers in multiple states.

At the end of the 2003, WIG officially launched the Challenge to Eliminate Cervical Cancer Campaign, which would continue educational efforts for policymakers, but also analyze and provide resources on the public policy side of this issue. As part of the Campaign, WIG developed numerous educational and outreach materials and researched the best existing materials, including peer reviewed medical journal articles, other groups' HPV/cervical cancer brochures and information on past legislative efforts. WIG also developed a public relations component, creating "sample" media documents for legislators to use in their local newspapers, radio stations and legislative newsletters.

In January 2004, WIG rolled out its first legislative toolkit for cervical cancer prevention and distributed a national press release detailing our effort. The legislative toolkit is one of the most important resources available to policymakers as it is designed to provide lawmakers with necessary background information, journal articles, fact sheets, and sample legislation, demonstrating best practices and successful policies

from across the U.S. WIG then convened a second meeting of the HPV and Cervical Cancer Task Force, whose participants were now more knowledgeable on the issues.

An important piece of feedback from both policymakers and the public health community was that the legislators often needed more data specifically regarding cervical cancer for their own states in order to advance their educational and policy efforts. As a result, WIG decided to take on the project of assembling existing data from the states to produce the first state-by-state report on cervical cancer prevention, which was released in January 2005. The report provided an overall assessment of the nation's progress in the fight against this preventable disease and featured state-specific data for several indicators, including incidence, mortality, health insurance and Medicaid coverage, and legislative efforts. The report is updated annually, enabling us to measure progress from year to year.

Also in 2005, WIG opened the HPV & Cervical Cancer Policy Resource Center, which provides legislators and the public with up-to-date information about cervical cancer policy, as well as news about new technologies and advances in cervical cancer prevention. The center also has basic information about HPV and cervical cancer in easy-to-share formats such as eCards (electronic greeting cards sent via email) and multimedia clips. The Resource Center produces print materials, such as fact sheets and brochures for policymakers to use with colleagues and constituents. The Resource Center also houses all of its information electronically on its website: www.womeningovernment.org/prevention.

WIG also began educating policymakers about HPV vaccines in development in 2005. New HPV vaccines entered the global market in 2006, and can prevent women from becoming infected with the 2 types of HPV that cause 70 percent of cervical cancers (Types 16 and 18). This new primary prevention strategy became a large part of our educational and outreach efforts, and was the focus of policy efforts in the following years.

In the first few years of the Campaign, WIG laid the groundwork for policy success by focusing early efforts on raising awareness about this disease and the new opportunities to prevent it. WIG also worked to ensure that legislators knew where they could find credible resources and help if they needed it. To further our work, we developed valuable partnerships with the medical, scientific, public health, advocacy, and business communities.

Education continues to play a critical role in cervical cancer initiatives – for new legislators and senior legislators as a refresher, when new technologies and medicines come to the market, and as new policies change at various levels of government.

Education

- WIG identified existing educational resources
- Created the following materials to support the Campaign:
 - Campaign fact sheet
 - Background information on available medical technologies
 - Model legislation packets
 - List of potential partners in the community
 - Document on how media relations can support efforts
 - Template media materials (sample press release, editorial, etc.)
- Distributed educational materials to policymakers and the community
- Utilized innovative approaches for getting the message out, such as reaching out to groups that already successfully engaged the public or to advocacy organizations that had a strong rapport with policymakers
- Convened educational sessions on cervical cancer and invited policymakers and other key stakeholders. Utilized experts in the field and ensured that all information was evidence-based and not politically biased
- Ensured that policymakers from all political backgrounds were engaged in this issue

PHASE TWO: POLICY DEVELOPMENT

By March 2005, one year after the Campaign's beginning, 36 states had introduced legislation aimed at eliminating cervical cancer and 15 had passed this legislation as a result of our Campaign. So how exactly did WIG determine which public policies to promote in our legislative toolkit and prioritize to our members?

The first step in any policy campaign is to identify the problems that need to be resolved – in the U.S. that included preventable incidence and death from cervical cancer, lack of health insurance for constituents, lack of public education, outdated policies that don't include access to new technologies or medicines, lack of funding for existing programs, poor uptake of vaccines, screening disparities, and cultural barriers. The problems that needed to be addressed, as well as the approach taken, varied by state and by country, depending on the structure of the healthcare system and cultural differences. After the problems were identified, our legislative members and staff conducted in-depth research and analysis on a wide range of ideas. For example, WIG looked at past experiences with similar policy challenges and determines what failed and what was successful. WIG consulted experts in the field and government agencies, looked at the infrastructure and feasibility of policies (i.e. funding availability, political climate), and asked groups that represent the people affected by HPV how they feel about the topic.

By 2006, there were four easily identifiable areas of policy development:

1. Access to new screening technologies
2. Access to vaccines
3. Education
4. Funding

Specific policy ideas were generated by the legislators, including:

- Establishment and funding for early detection, prevention and treatment programs
- HPV and vaccine education programs in schools for kids and parents

- Resolutions to designate January as Cervical Cancer Awareness Month
- Mandatory insurance coverage of HPV vaccines, HPV testing, and Pap tests
- Unrestricted Medicaid Coverage of HPV Testing and resolutions to support congressional legislation around cervical cancer prevention
- Mandatory vaccination for school enrollment
- Study committees to evaluate the implications of mandatory vaccinations
- Creation of breast cancer license plate to fund breast and cervical cancer programs
- Creation of cervical cancer task forces
- Laws that utilize funds from tobacco settlements to fund breast cancer and cervical cancer programs

By January 2006, two years into our Campaign, 42 states had introduced legislation for cervical cancer prevention and 36 states had enacted this legislation as a result of our Campaign. The types of policies put in place by our members were across the spectrum and covered many of the policy ideas listed above. That same year, our HPV and Cervical Cancer Task Force issued formal policy recommendations on behalf of WIG.

Policy Development

- WIG evaluated the current cervical cancer prevention landscape in each jurisdiction; for example:
 - What is the burden of cervical cancer?
 - Where does the burden lie (socio-economically, racial/ethnic, etc.)?
 - Do formal screening and treatment programs exist?
 - Does a formal vaccination program exist?
 - What are the funding challenges?
 - Are the programs already in place adequately funded?
 - What barriers exist for access to healthcare (financial, cultural, etc.)?
 - How educated are the public and policymakers about cervical cancer?
 - What role do women play in government? Are there women who play a prominent role in the community in another form (i.e. school groups, religious organizations, etc.)?
 - What is the political climate surrounding cervical cancer prevention?
 - What policies are in place for cervical cancer prevention?
 - What policies have failed?
 - What policies are pending?
 - Who has supported these policies? Who has opposed these policies?
 - What are the un-intended consequences of policies?
- After identifying the problem(s) and assessing the climate (including past successes and failures), we developed policy solutions with key stakeholders and designated a committee (i.e. Board of Directors or advisory groups) to sign off on these ideas and evaluate them on a regular basis
- Continually re-assessed policy needs and evaluate current policies

PHASE THREE: ADVANCING GOVERNMENT EFFORTS THROUGH NON-GOVERNMENT PARTNERSHIPS

WIG has partnered with several non-governmental organizations throughout the Campaign. These have established WIG as a reliable source for information about cervical cancer prevention. In return for providing a policy perspective to national dialogues about cervical cancer prevention, our partner organizations have given WIG greater access to medical expertise, cervical cancer survivors, and the support of their advocacy networks, which have greatly contributed to the success of the Campaign.

While our organization has a highly committed group of legislative members, WIG learned early on that collaboration with non-governmental stakeholders is critically important for success. Many potential partners have significant credibility with their constituents in ways that WIG did not. WIG worked with three key partner groups to garner the attention of particular audiences: the Balm in Gilead, Hadassah, and the Coalition of Labor Union Women.

The first step in working with potential partners was to establish common ground. One easy way WIG worked with potential partners to understand our efforts and perspective was to invite them to one of our educational meetings. It's important to WIG for partners to see what we do and to meet our membership. For example, throughout 2005, WIG held state briefings with legislators and other stakeholders in several states, including New York, Pennsylvania, West Virginia, Illinois and Hawaii. The legislators invited WIG to host a briefing in their state to share important education with policymakers and stakeholders to advance cervical cancer prevention. By including existing and potential partners in these briefings the important message of cervical cancer prevention and the need for policy change with the policymakers in attendance was enhanced. The briefings often resulted in new legislation being introduced, or existing legislation being further advanced.

WIG officially partnered with the National Organization of Black Elected Legislative Women (NOBEL/Women) at our Southern Regional Conference that year. WIG also opened up the lines of communication and information exchange with the Centers for Disease Control and Prevention. One of our most important partnership-building activities to date was our partnership with the CDC, through which WIG convened the first annual HPV and Cervical Cancer Summit. The Summit will be discussed in further detail in the next section.

The introduction of this document discussed challenges the Campaign faced. Working with other organizations and stakeholders is a critical component to moving any campaign forward, but establishing a group consensus for the group's direction is very difficult. After our first HPV & Cervical Cancer Task Force, WIG convened multiple stakeholders in cancer prevention to discuss joint efforts to address cervical cancer. The meeting concluded with some ideas for collaboration, but did not produce everything WIG had hoped for. The challenge at this meeting was working toward consensus on all the specifics of the collaboration, which is often difficult. Many organizations have their own guidelines about how they create advocacy materials, or what they are willing to discuss with their members. WIG learned that it is important not to compromise our overall objectives, but that compromise on less important details may be necessary to move the collaboration forward.

Advancing Government Efforts through Non-Government Partnerships

- WIG determined the type of partners needed and how they might support WIG.s efforts
- Identified potential partners, such as:
 - Community organizations
 - Religious groups
 - Schools
 - Medical providers/groups
 - The scientific community
 - Cancer prevention advocates
 - Academia
 - Cancer patients and survivors
 - Women’s organizations
 - The business community
 - The media
- Ensured that the selection of partners was credible and contributed to overall goals
- Approached potential partners and established common interests
- Was clear about partner expectations
- Found ways to support partners
- Learned from partners successes and failures, but always stayed true to message and took leadership over programming
- A common and shared message between partners was powerful, but did not compromise on the message
- Identified the messages or goals we were willing to compromise on and those we were not

PHASE FOUR: LEVERAGING PARTNERSHIPS & SUPPORTING POLICYMAKERS

To continue our educational efforts and aid policymakers in introducing and enacting legislation, WIG worked with many of our partner groups to engage wider audiences in supporting legislators’ initiatives. In 2006, WIG held additional state briefings that featured expert speakers and survivors and showcased policy models in Oklahoma, West Virginia, California, Florida, and New York. WIG also worked with partner organizations to present at their annual or semi-annual conferences to further educate and engage their members.

Building a network of contacts throughout the country was critical to supporting legislators’ efforts in all the states. WIG holds annual Regional Conferences and state briefings to present the perspectives of their organizations’ members and lend their support to the public policies that would eliminate cervical cancer. Continuing to use the strengths of our partner organizations, such as medical expertise, allowed us to engage new players, and keep our members interested and informed on the topic.

One specific example from 2007 is a state briefing in California, where WIG held a luncheon and brought in an expert clinician to talk about cervical cancer and HPV, had a survivor share her story, and allowed partner organizations, including the Coalition of Labor Union Women, to share their efforts with other constituencies. As a result of the briefing, legislation in California passed requiring health insurance coverage for HPV testing. In addition to the briefing’s success in supporting this legislative activity, the Coalition of Labor Union Women also introduced a letter writing campaign with their members in

California in which they contacted their state legislator urging them to support the legislation. Members also wrote opinion-editorials for their local papers increasing media attention of this policy issue in the state.

As noted in the California example, working with the media was an important aspect of our campaign's success. The power of the media to disseminate information to the public and garner attention from government leadership can bring an issue from obscurity to a national debate overnight. While WIG did not put cervical cancer on the national agenda overnight, use of the media was a critical component of our overall success. Launching the campaign was an important media opportunity for WIG. As WIG further developed strategies and policy solutions, leveraging media opportunities throughout the campaign helped to keep the issue on the agendas of state legislatures and increased public awareness of HPV and cervical cancer prevention.

In addition to disseminating press releases and working with the media to attend and cover the annual HPV Cervical Cancer Summits, WIG had the unique opportunity to engage the media in chronicling the campaign. Media persons conducted interviews with leading expert speakers and legislators to showcase the most up-to-date information about HPV and cervical cancer as well as new opportunities for prevention. WIG facilitated interviews for members working on legislation on this issue, allowing them to share their perspectives with their colleagues and constituents through the press. WIG used media opportunities to highlight the entire campaign and demonstrate the need for policy change.

Our largest media opportunity came with the release of our annual state-by-state comparison report. This annual media opportunity to show state performance in cervical cancer prevention demonstrates to policy leaders that more must be done to address this issue. In addition to a national press release from WIG, we provide our members with opinion-editorials and template press materials to facilitate their own interviews about their activities and on the status of cervical cancer prevention in their states.

Other opportunities throughout the campaign to leverage relationships with the media and partner organizations include national awareness events, such as a Cervical Cancer Prevention Month and Women's Health Week. Working with partners to send out information on these topics at the same time as WIG did, and doing so during a national awareness activity, increased our visibility on this issue with the media and our constituency.

Partnering with organizations that have complementary areas of expertise is an effective way to create materials that add credibility to an initiative. In 2007, WIG worked with the American Medical Women's Association (AMWA), an organization of female physicians across the country, to produce and co-market a brochure intended for the general public on cervical cancer and prevention opportunities. By joining with AMWA, WIG created a resource that was accurate and useful for multiple audiences.

After the introduction of the HPV vaccine in 2006, WIG traveled to Guatemala with the Pan American Health Organization to present at their "HPV Vaccine Introduction Meeting." This meeting was an excellent opportunity to see firsthand the need for new technologies in the developing world. While many of the challenges were different for stakeholders in Latin America and the Caribbean, many of the barriers were similar to those in the U.S.

Another international opportunity occurred in Ireland in 2006, where WIG met with the Minister of Health and leaders in the cancer prevention field. By sharing our experiences, WIG assisted Ireland in working to implement a national screening program for women. More than the opportunity to engage with the international community, these experiences have allowed us to garner feedback on the infrastructure needs and opportunities for policy throughout the world. These opportunities have also created new partnerships for WIG across the globe.

Our HPV & Cervical Cancer Summit continues this important dialogue on a yearly basis, bringing together many stakeholder groups – legislators, public health agency officials, and policy and health advocates – to discuss opportunities for advancing efforts in cervical cancer prevention. For the past four years our Summit has convened nearly 100 participants to discuss relevant and timely issues in cervical cancer prevention. Each Summit features advocacy partners, legislators, public health officials and others who share best practices and activities from the previous year. WIG also engages the world’s leading experts to review cervical cancer prevention opportunities for women of different ages, socio-economic backgrounds, and cultural beliefs. The Summit includes presentations on the cost-effectiveness of prevention and new strategies to deliver lifesaving technologies to those most in need. The 2008 Summit featured discussions on global efforts to eliminate cervical cancer, particularly in developing countries where the burden of disease is disproportionately high.

As a result of the discussion at the first Summit in 2005, WIG produced a white paper to be disseminated nationally to help guide efforts in the states toward successful policy introduction, enactment, and implementation. Strategies presented in the white paper also outlined the role of other stakeholders, including clinicians and community members. Including clinicians, advocates and agency officials in the Summit broadened the scope of policy development discussions to incorporate the implementation and follow-up of legislation. This expanded focus helps legislators better understand the impact of their efforts on the implementing agencies and what additional resources are required to fully act on policymakers’ efforts. These strategies allow us to work with partner organizations and provide a starting point for collaborative efforts in the states.

Leveraging Partnerships & Supporting Policymakers

- Worked with partners to lend credibility to efforts (e.g. using physicians from a partner organization to share clinical information) and engaged partner constituencies in support of legislative efforts
- Invited partners to present their efforts at meetings and conferences to show and create synergies in activities
- Presented at partner’s meetings to showcase campaign efforts and garner support
- Produced materials with partners or coordinated outreach to garner media attention
- Leveraged national awareness activities, such as cervical cancer prevention month or women’s health week
- Shared best practices with partner organizations to support success of a campaign inside the country and across borders

CONCLUSION

By the end of September 2007, all 50 states had introduced and/or enacted legislation aimed at cervical cancer prevention. The Campaign continues to garner attention and spur legislative activity, helping to increase awareness about HPV and its link to cervical cancer, pursuing new education and advocacy efforts, engaging new legislators, working with new partners, and expanding our reach.

The Campaign began as a domestically focused program, but in the past several years WIG broadened its focus to include global cervical cancer advocacy. After many successes in the U.S., WIG began to work with international partners. As early as 2005, WIG began participating in international forums on cervical cancer prevention, including the 2005 International Papillomavirus Conference in Vancouver, the 2005-2008 Eurogin Conferences, and individual country and organization meetings. In 2006, WIG traveled with the Pan American Health Organization to Guatemala, as noted above, to discuss the introduction of the HPV vaccine in partner countries. This experience reinforced the need to work with the global community to increase education and awareness about HPV and cervical cancer, and bring lifesaving testing and vaccines for cervical cancer to other regions of the world. At the end of 2006, WIG also participated in a Canadian HPV and Cervical Cancer Summit, modeled after our own annual Summit. In 2007, WIG met with the World Health Organization, presented at the First Global Summit on HPV & Cervical Cancer in Paris, France, and participated in the 20th World Cancer Congress in Geneva, Switzerland in 2008. Also in 2008, WIG joined with the European Cervical Cancer Association (ECCA) to launch the “Pearl of Wisdom Campaign” in the U.S. WIG also participated in ECCA’s Cervical Cancer Summit in Brussels, Belgium. This summit was an opportunity for WIG to share campaign best practices with representatives from European Union member states, parliamentarians, and European organizations with an interest in eliminating cervical cancer. WIG’s campaign was highlighted as a highly successful effort to eliminate cervical cancer.

WIG created this toolkit and other tools to aid stakeholders in other countries in creating political will for cervical cancer prevention. WIG aims to create new or renewed enthusiasm and energy around HPV and cervical cancer prevention globally, and in particular, in the areas of the world with a disproportionate burden of cervical cancer. WIG looks forward to continuing this initiative in the U.S. and across the globe, and hopes this document can serve as a resource to those who wish to initiate a campaign in their own country. WIG stands ready and willing to support those efforts, to reach the goal of eliminating cervical cancer.