State of Illinois
Rod R. Blagojevich, Governor

Department of Public Health
Eric E. Whitaker, M.D., M.P.H., Director

Cervical Cancer Task Force Annual Report

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Illinois Department of PUBLIC HEALTH

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MEMBERS	CRITERIA ESTABLISHED BY LAW
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Yvonne Collins, MD, Assistant Professor University of Illinois at Chicago Gynecologic Oncology 820 S. Wood St. - MC 808 Chicago, IL 60612	Representative of a national organization relating to cancer treatment who is an oncologist.
Stephani Huston Cox, NP, Colposcopist Director of Patient Services Planned Parenthood Springfield Area 1000 E. Washington St. Springfield, IL 62703	Representative from an organization relating to women and cancer.
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L. Stewart Massad, MD, Associate Professor and Chief Division of Gynecologic Oncology Department of Obstetrics and Gynecology SIU School of Medicine, P.O. Box 19640 Springfield, IL 62794-9640	A member of the IBCCP medical Advisory Committee.
Elizabeth S.A. Patton, RN, Administrator East Side Health District 3121 Virginia Place East St. Louis, IL 62203	A licensed registered nurse.
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LEGISLATED TASK FORCE MEMBERSHIP

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As required by the State Officials and Employees Ethics Act (5 ILCS 430/), which became law in December 2003, all state board appointees were required to take the 2005 Governor's Ethics Training Program for Board and Commission members, and complete the Acknowledgement of Participation form.

LEGISLATED TASK FORCE MEMBERSHIP

EX-OFFICIO MEMBERS	REPRESENTS
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Special thanks to The Virginia Governor's Task Force on Cervical Cancer whose work on this issue provided a model for our work.

MISSION

The mission of the Cervical Cancer Elimination Task Force is to develop a plan to eliminate cervical cancer in Illinois.

The task force goals are to:

- Review data and analyses regarding the prevalence and burden of cervical cancer in Illinois.
- Coordinate the efforts of the task force with existing state programs that provide cervical cancer screening, education and case management.
- Raise public and professional awareness on the causes, risks, prevention, early detection and treatment of cervical cancer.
- Review costs and reimbursement rates for screening and treatment.
- Identify strategies to inform the public about new technologies related to cervical cancer.
- Identify strategies to enhance provider efforts at cervical cancer elimination.
- Examine existing laws, regulations, programs and services that impact access to screening and treatment.
- Improve access to care for underserved women.
- Eliminate health disparities.
- Develop a statewide comprehensive Cervical Cancer Prevention Plan and strategies to implement and promote it.
- Receive and consider reports and testimony from the general public and from public and private organizations on their services and recommendations to improve cervical cancer prevention, diagnosis and treatment.

EXECUTIVE SUMMARY

Every year in Illinois hundreds of women needlessly die from cervical cancer. This is of concern because cervical cancer is preventable and when detected early and treated the prognosis is excellent. In its recent report, *Excess Cervical Cancer Mortality: A Marker for Low Access to Health Care in Poor Communities,* the National Cancer Institute argues high rates of cervical cancer mortality are an indication of other health care issues that need to be addressed.

In Illinois, there are substantial racial, ethnic and regional disparities for cervical cancer incidence, mortality and stage of diagnosis. Every Illinoisan has a vested interest in addressing such disparities and ensuring all women have access to appropriate preventive screenings and timely access to life saving treatments. By addressing the causal factors of cervical cancer, it is likely that the overall health of women, especially those at high-risk for this cancer, may be improved.

Pap test screening is key in detecting precancerous conditions. There are currently many private and public organizations providing these services in Illinois. However, women continue to forgo screening due to cultural, economic and/or educational factors. Additionally, the highly prevalent human papillomavirus (HPV) infection, for which there is no cure, is known to be the leading cause of cervical cancer. Recent research shows it is linked to 99.7 percent of all cervical cancer cases. Sadly, many women and men remain unaware of this fact.

Compounding these issues are various barriers to management and treatment services for precancerous conditions. Although some publicly funded programs for women needing such services exist, many women do not qualify. For these women, the expense and travel associated with procuring management and treatment services have an influence on when and if timely, life-saving services will be sought and/or obtained.

In August 2004, Gov. Rod R. Blagojevich signed legislation to create a Cervical Cancer Elimination Task Force. The new law was sponsored by Sen. Debbie DeFrancesco Halvorson of Crete and Rep. Sara Feigenholtz of Chicago. The Governor charged the group with three responsibilities:

1. Studying the prevalence of the disease;

2. Raising public awareness about the causes; and,

3. Developing a statewide comprehensive prevention and control plan.

As state public health director, Dr. Eric E. Whitaker appointed the 12-member task force, which includes physicians, health professionals and community-based advocacy groups. The director appointed Dr. Stacie Geller, Associate Professor, Department of Obstetrics and Gynecology at the University of Illinois at Chicago, to chair the task force. Members of the General Assembly and representatives from state agencies serve as ex-officio members. The Illinois Department of Public Health's Office of Women's Health provides staff support to the group. A report on the task force's work to date will be presented to the Governor and General

Assembly on April 1, 2006. Annual reports will be due each year thereafter, with the task force to expire on April 1, 2009, or sooner, upon submission of a final report.

The major reason the task force was created is that cervical cancer is a preventable and curable disease. While the mortality rate of cervical cancer has dropped by 70 percent since the introduction of the Pap test, women continue to suffer and die from cervical cancer. In fact, an estimated 630 Illinois women will be diagnosed with cervical cancer this year and 220 will die from the disease. The two strategies needed to continue to reduce the mortality rate from cervical cancer is to motivate women to take charge of their health by scheduling regular Pap tests and to increase awareness of HPV.

Cervical cancer is almost always caused by human papillomavirus, or HPV, which is the most common sexually transmitted disease in America. Approximately 75 percent to 80 percent of Americans have HPV at some point of their lives. This virus can live in the body for many years and, for most people, causes no ill effects and disappears on its own. In rare cases, certain strains can cause cervical cancer, but of the 20 million Americans currently infected with HPV, far less than 1 percent will develop cervical cancer.

The task force has developed a communications strategy targeting both healthcare professionals and consumers to increase knowledge of the need for Pap tests and HPV, particularly among demographic groups that show heightened incidences and mortality rates for cervical cancer. Specific recommendations are identified later in this report.

BURDEN OF DISEASE

INCIDENCE

Cervical cancer is a relatively common cancer, although it is not among the five most common cancers in Illinois or the United States (Table 1).1 Breast cancer was the most commonly reported cancer in both Illinois, where the age-adjusted rate was 128.4 per 100,000 women, and the U.S. as a whole (134.4 per 100,000). The rates of lung and bronchus cancer, colorectal cancer, uterine cancer, and Non-Hodgkin Lymphoma all rank in the top 10 most common cancers for both Illinois and the U.S. Cervical cancer, which had an age-adjusted incidence rate of 11.6 per 100,000, was the seventh most common cancer diagnosed among females in Illinois in the years 1986 – 2002. An estimated 630 Illinois women will be diagnosed with cervical cancer this year and 220 women will die of the disease. It is the 11th most common female cancer in the U.S. with a rate of 8.9 per 100,000 from 1998-2002. More than 700,000 cases of high-grade cervical dysplasia occur each year in the United States[2]. Roughly 500,000 to one million women will develop high-grade cervical cancer precursors each year, and all will need treatment. Identifying these precursors is expensive and difficult. Hundreds of thousands of Illinois women will be found to have abnormal Pap tests each year, and identifying those with cancer precursors will require millions of dollars and thousands of hours of time lost from work. Treatments require destroying affected portions of the cervix, which can predispose to miscarriage and preterm delivery.

TABLE 1

Age Adjusted Incidence Rates of Common Cancers among Females, Illinois* and United States. (per 100,000)

Site	Illinois	United States
Breast	128.4	134.4
Lung and Bronchus	49.2	48.9
Colorectal	51.4	46.0
Corpus and Uterus, NOS	24.8	24.3
Non- Hodgkin Lymphoma	14.6	15.8
Ovary	14.7	13.9
Cervix	11.6	8.9
Melanoma of the Skin	7.9	14.0
Thyroid	8.2	11.1
Pancreas	9.7	9.8
Urinary Bladder	9.7	9.1

*Illinois: 1986-2002 average
**U.S.: 1998-2002
Source: ICR 2005; SEER Cancer Statistics Review 1975-2002

[1] Illinois Cancer Registry (ICR) 2005, SEER Cancer Statistics Review 1975-2002
[2] Results from the National Breast and Cervical Cancer Early Detection Program, October 31, 1991-September 30, 1993. MMWR Morb Mortal Wkly Rep 1994;43:530 -4.

The highest incidence rates statewide appear in relatively remote, rural counties, such as Jo Daviess, Henderson, Pike, Crawford, Lawrence, Washington, Jefferson, Johnson and Pulaski as shown in Figure 1. As shown in Figure 2 mortality rates are highest in Edwards, Perry and Hardin indicating there is not a close relationship between new cases of disease and death from disease. Interpretation of the data should be made with care due to the very small numbers of cases reported in these smaller, rural counties. Figure 3, which highlights the cervical cancer incidence by zip code in Cook County, shows the highest incidences of the disease in the low income, minority areas on the city of Chicago's south, west and northwest sides.

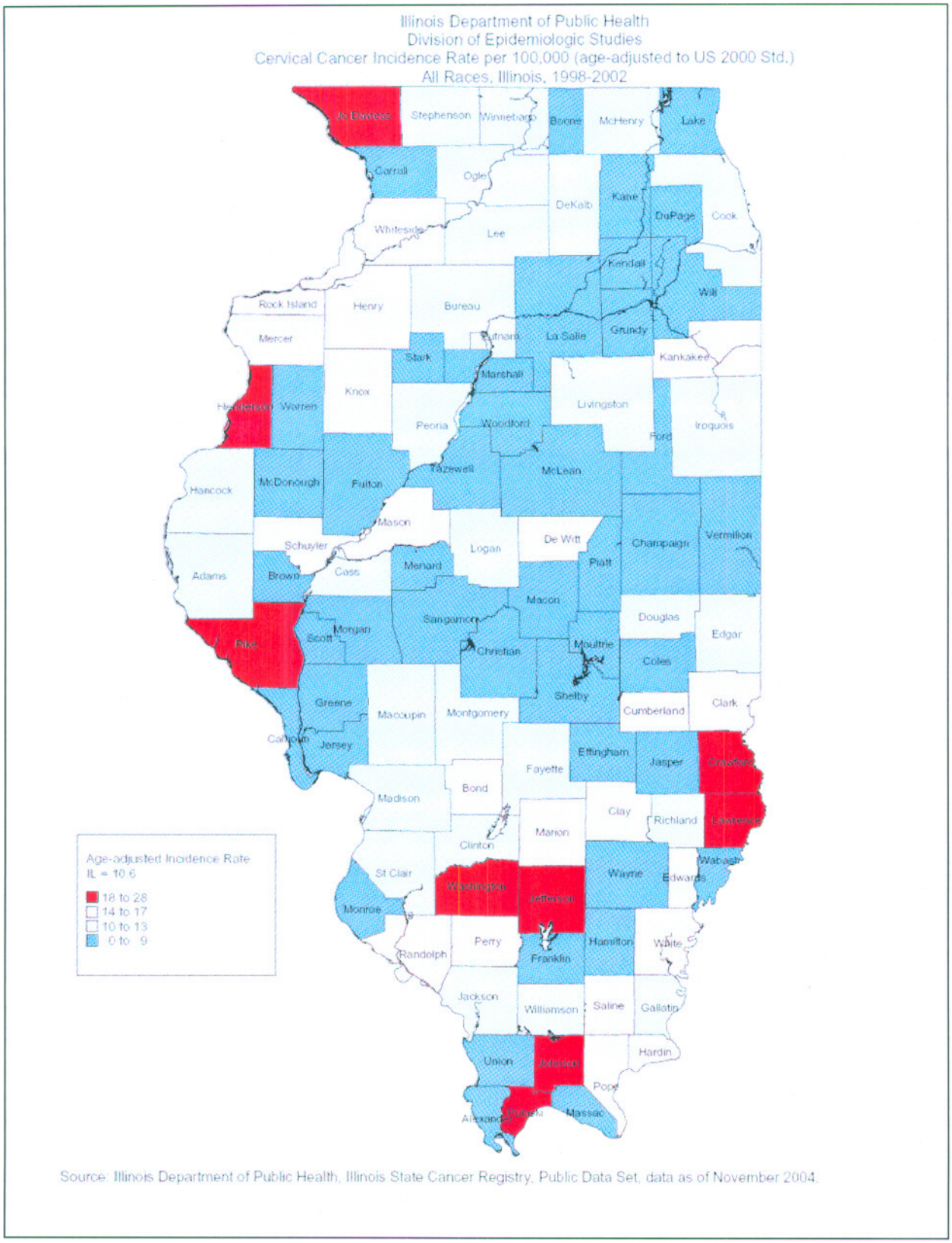
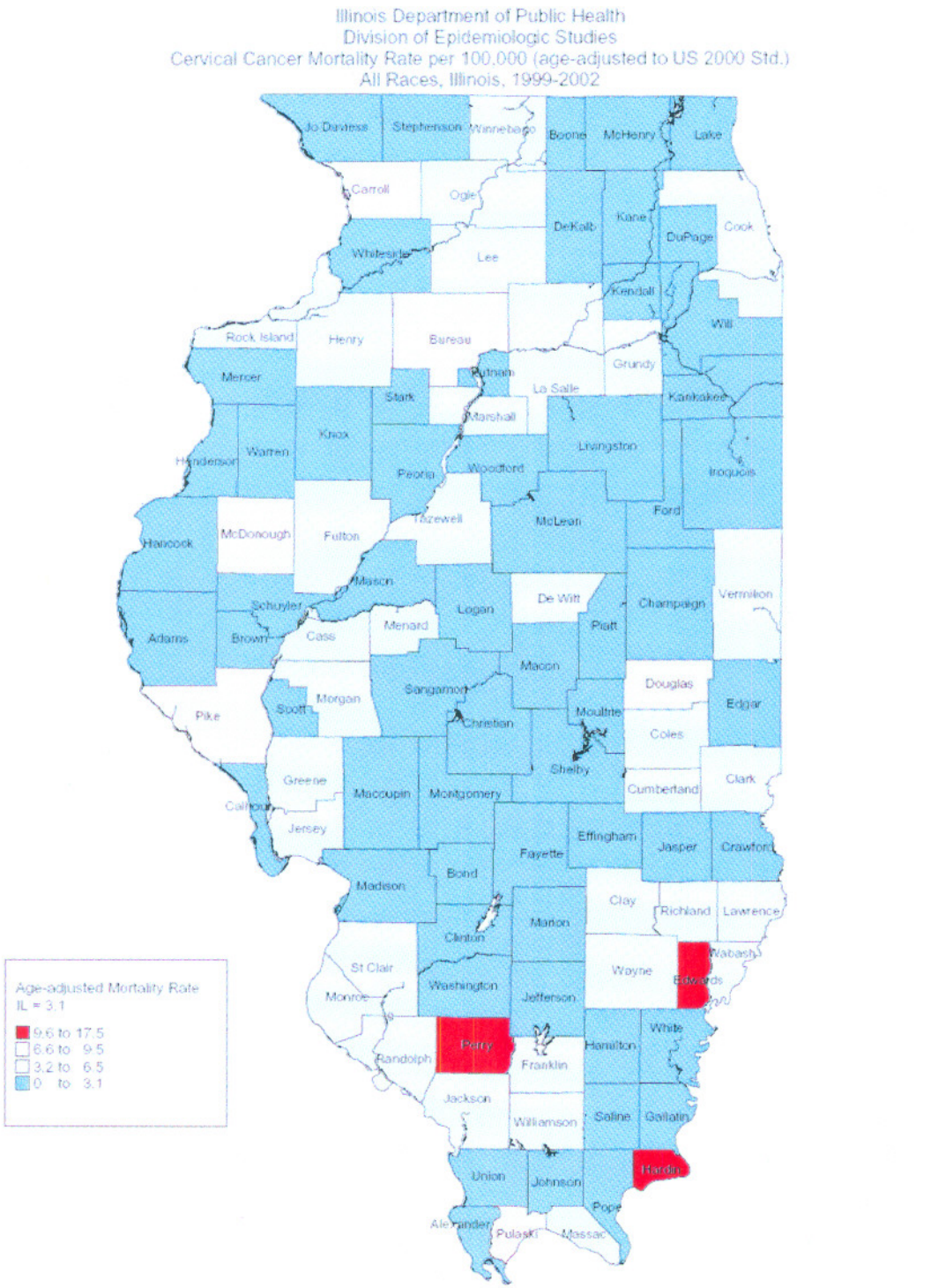

Illinois Department of Public Health
Division of Epidemiologic Studies
Cervical Cancer Incidence Rate per 100,000 (age-adjusted to US 2000 Std.)
All Races, Illinois, 1998-2002
Jo Daviess
Stephenson
Winnebago
Boone
McHenry
Lake
Carroll
Ogle
DeKalb
Kane
DuPage
Cook
Whiteside
Lee
Kendall
Will
Rock Island
Henry
Bureau
Mercer
Putnam
La Salle
Grundy
Kankakee
Stark
Marshall
Knox
Henderson
Warren
Livingston
Peoria
Woodford
Iroquois
Ford
Tazewell
McLean
Hancock
McDonough
Fulton
Mason
Schuyler
Logan
De Witt
Champaign
Vermilion
Adams
Brown
Cass
Menard
Piatt
Macon
Douglas
Edgar
Pike
Morgan
Scott
Sangamon
Christian
Moultrie
Coles
Greene
Macoupin
Montgomery
Shelby
Cumberland
Clark
Calhoun
Jersey
Effingham
Jasper
Crawford
Fayette
Bond
Madison
Clay
Richland
Lawrence
Clinton
Marion
St Clair
Wayne
Wabash
Edwards
Washington
Jefferson
Monroe
Perry
Hamilton
White
Randolph
Franklin
Jackson
Williamson
Saline
Gallatin
Union
Johnson
Hardin
Pope
Alexander
Pulaski
Massac
Age-adjusted Incidence Rate
IL = 10.6
18 to 28
14 to 17
10 to 13
0 to 9
Source: Illinois Department of Public Health, Illinois State Cancer Registry, Public Data Set, data as of November 2004.

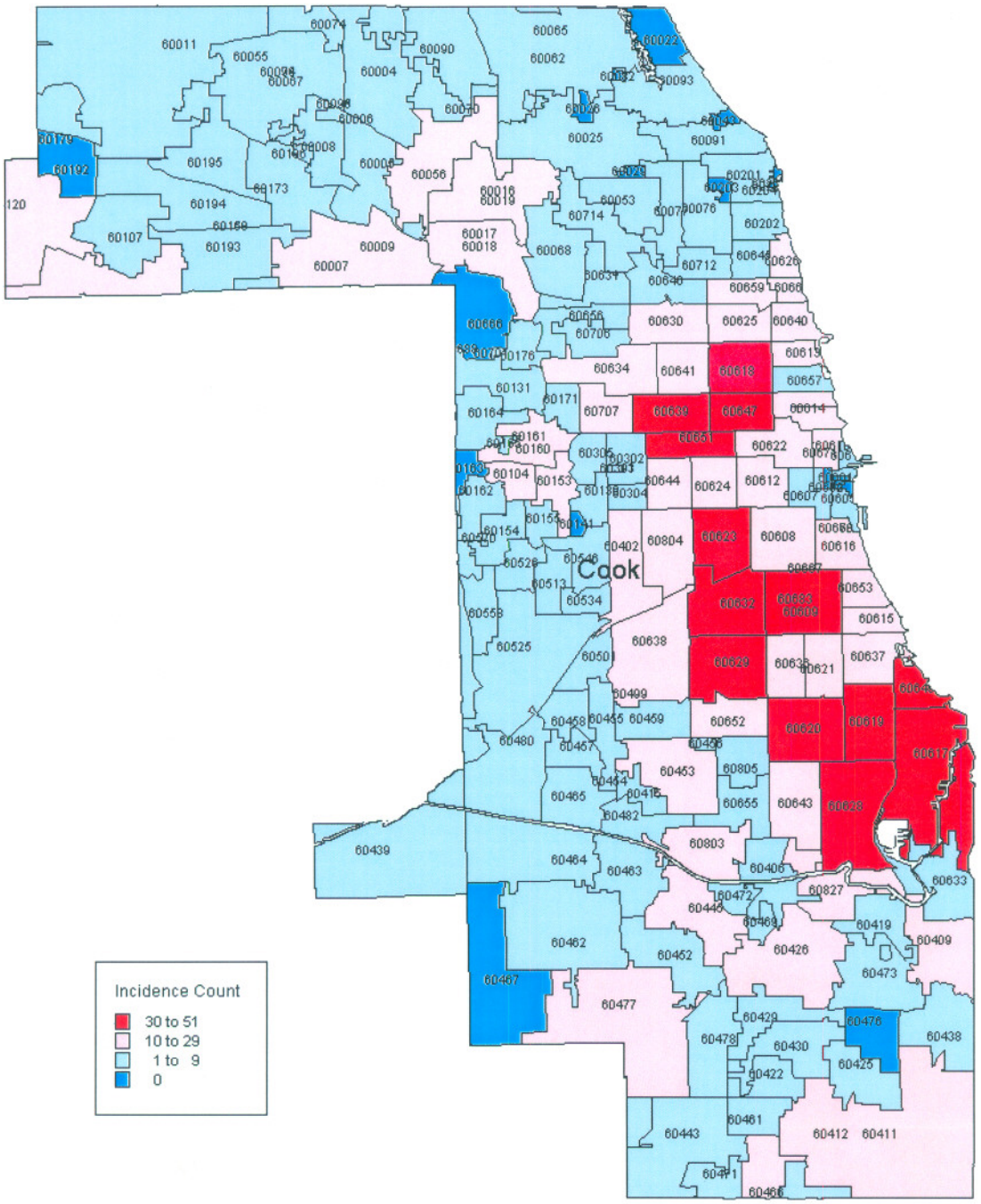
Figure 1



Source:Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Mortality - All COD, Public-Use With County, Total U.S. (1969-2002), National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2005. Underlying mortality data provided by NCHS (www.cdc.gov/nchs).

Figure 2

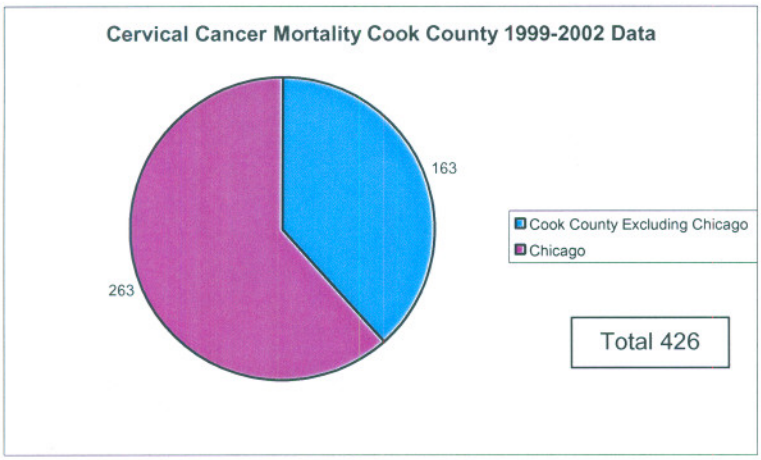
Illinois Department of Public Health
Division of Epidemiologic Studies
Five-year Cervical Cancer Incidence Counts by ZIP Code Area
Cook County Illinois, 1998-2002



Source: Illinois Department of Public Health, Illinois State Cancer Registry, Public Data Set, data as of November 2004.

Figure 3

In Cook County, 62 percent of the cases of cervical cancer occurred in the city of Chicago as shown below.



As shown below, cervical cancer age-specific incidence rates continue to increase after age 50 among blacks and Hispanics, especially in Cook County. This is not true among whites.

Cervical Cancer Age-specific Incidence Rates,
Cook vs. Downstate, Whites, Illinois, 1998-2002

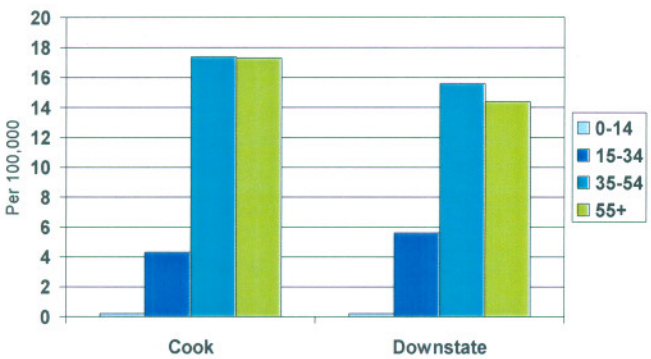


Figure 4

Cervical Cancer Age-specific Incidence Rates,
Cook vs. Downstate, Blacks, Illinois, 1998-2002

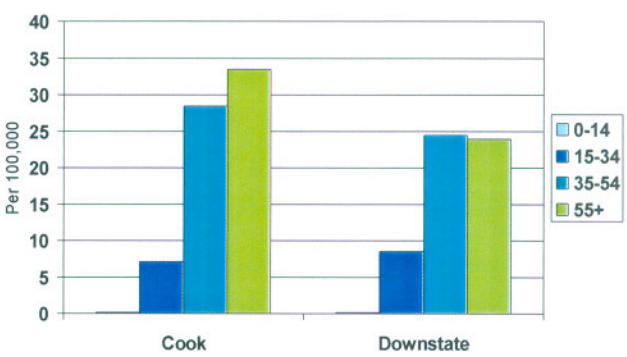


Figure 5

Cervical Cancer Age-specific Incidence Rates,
Cook vs. Downstate, Hispanics, Illinois, 1998-2002

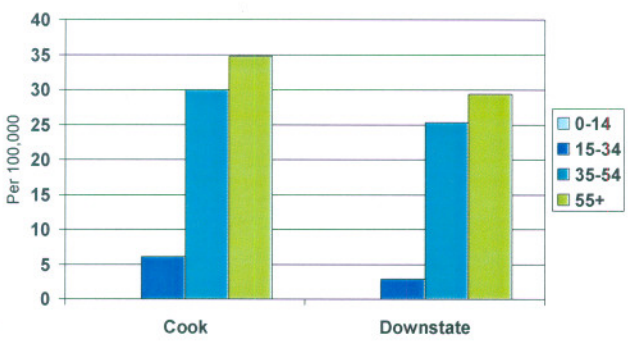


Figure 6

Trend data indicates that Hispanic women's incidence rates parallel African-American women until age 80 when there is a sharp rise among Hispanic women (Figures 7 and 9). This trend is mimicked in mortality rates based on data from 1999-2002 (Figures 8 and 10). There are two distinct increases in incidence rates among blacks after age 50. Indications to support the first increase are that these women become Medicare eligible and, therefore, additional screening is identifying more disease. Cultural perspectives that may address why women may not get screened, include the fact that many of the women may no longer menstruate and do not realize the importance of continued screenings, the physical discomfort associated with the screening, patient uneasiness disrobing around anyone other than their spouse and language barriers. The issue of "stigma" attached to having HPV, especially in the older population, also may contribute to the lack of appropriate screening of this population.

Cervical Cancer Age-specific Incidence Rates,
Whites, Blacks, and Hispanics, Illinois, 1998-2002

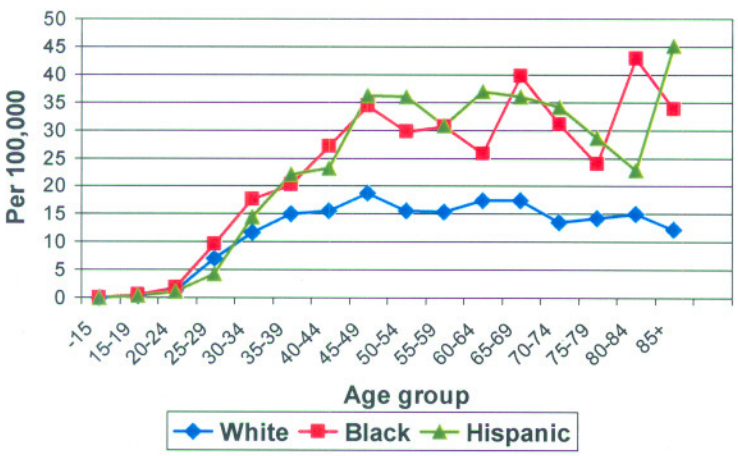


Figure 7

Cervical Cancer Age-specific Mortality Rates,
Whites, Blacks, and Hispanics, Illinois, 1999-2002

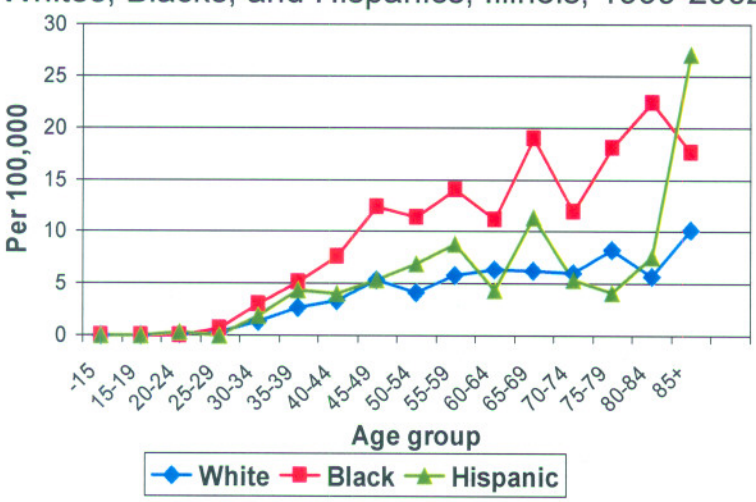
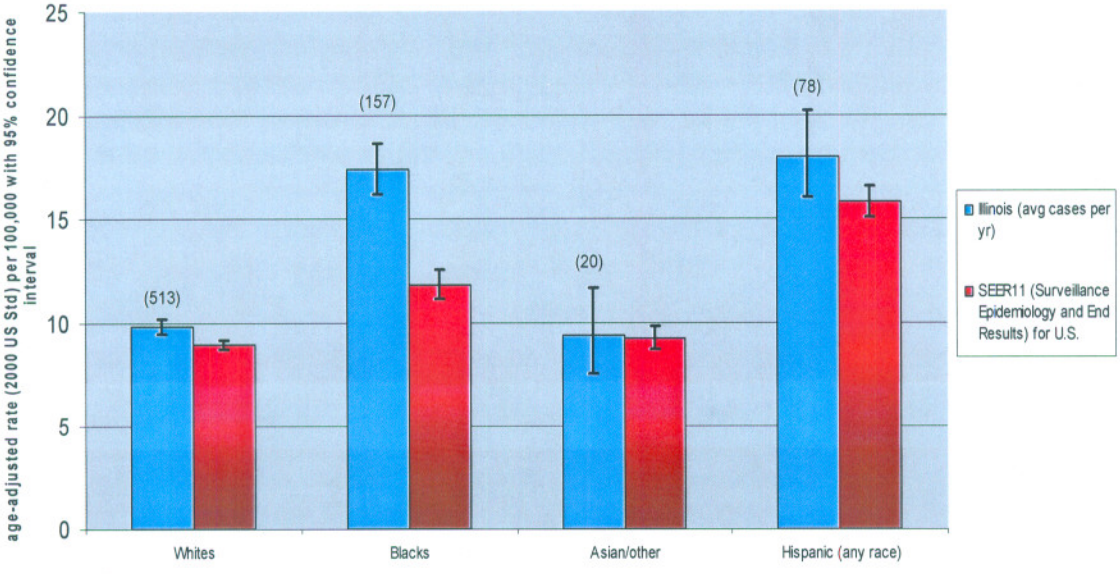


Figure 8

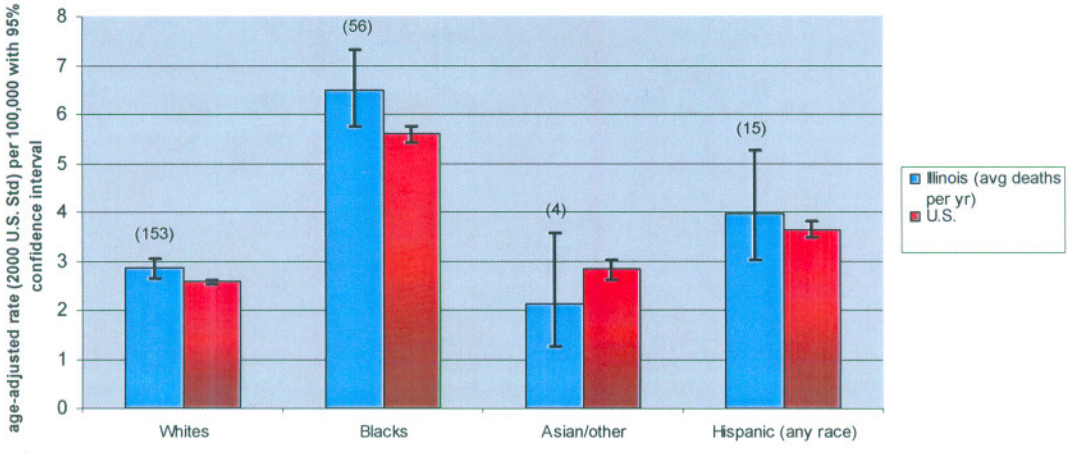
Cervical Cancer Age-adjusted Incidence Rates, by Race and Ethnicity
Illinois and United States, 1997-2001



Source: Illinois data: Illinois Department of Public Health, Illinois State Cancer Registry, November 2003. U.S. data: SEER 11 Registries, November 2003 submission, National Cancer Institute, DCCPS, Surveillance Research Program

Figure 9

Cervical Cancer Age-adjusted Mortality Rates, by Race and Ethnicity
Illinois and United States, 1997-2001



Source: Data obtained from the National Center for Health Statistics, data released April 2004.

Figure 10

OVERVIEW AND THE ROLE OF HUMAN PAPILLOMAVIRUS (HPV) IN THE DEVELOPMENT OF CERVICAL CANCER

HPV is a member of a family of viruses that can cause abnormal cell proliferation. Different HPV types are linked to skin and genital warts, cervical dysplasia and various cancers. Of the more than 100 types of HPV, about 30 are transmitted sexually, which can then affect the genital tract.[3] About 14 types of sexually transmitted HPV have been linked to cervical cancer and are considered high-risk strains.[4]

HPV infections, for which there is no cure or treatment, are common. Genital HPV infections are believed to be the most prevalent sexual transmitted infections (STI) in the U.S., resulting in roughly 20 million people currently infected. Of those, 50 percent to 75 percent are infected with high-risk strains of HPV.[5] Additionally, current evidence suggests that more than half of sexually active women have been infected with HPV.[6] Maximum prevalence occurs between ages 20-24, with a decrease in prevalence until age 35 followed by a further decrease after age 50.[7]

Recent studies have shown that high-risk HPV is present in more than 99.7 percent of cervical cancer cases worldwide.[8] HPV-16 accounts for about half of all cervical cancers and HPV types 18, 31, 33 and 44 combined account for an estimated 20 percent.[9] Before cancer appears in the cervix, the cells of the cervix go through precancerous changes known as dysplasia. Although a Pap test is not a test for HPV, the cell changes resulting from HPV infections are often detected when a women has a Pap test.

Research suggests that persistent HPV infections are the most critical for later development of cervical cancer.[10] As shown in Figure 11, which depicts the relationship between HPV infection and the development of cervical cancer, 80 percent of HPV infections regress spontaneously.[11] Additionally, studies show that 91 percent of new HPV infections will clear within two years. In a small minority of women, the infection persists and may result in genital warts, cervical dysplasia or cervical cancer.[12] Furthermore, cervical dysplasia (precancerous conditions) resulting from HPV infections also is more likely to regress or persist unchanged than to progress to invasive cancer.[13] It is important to note that once HPV infection

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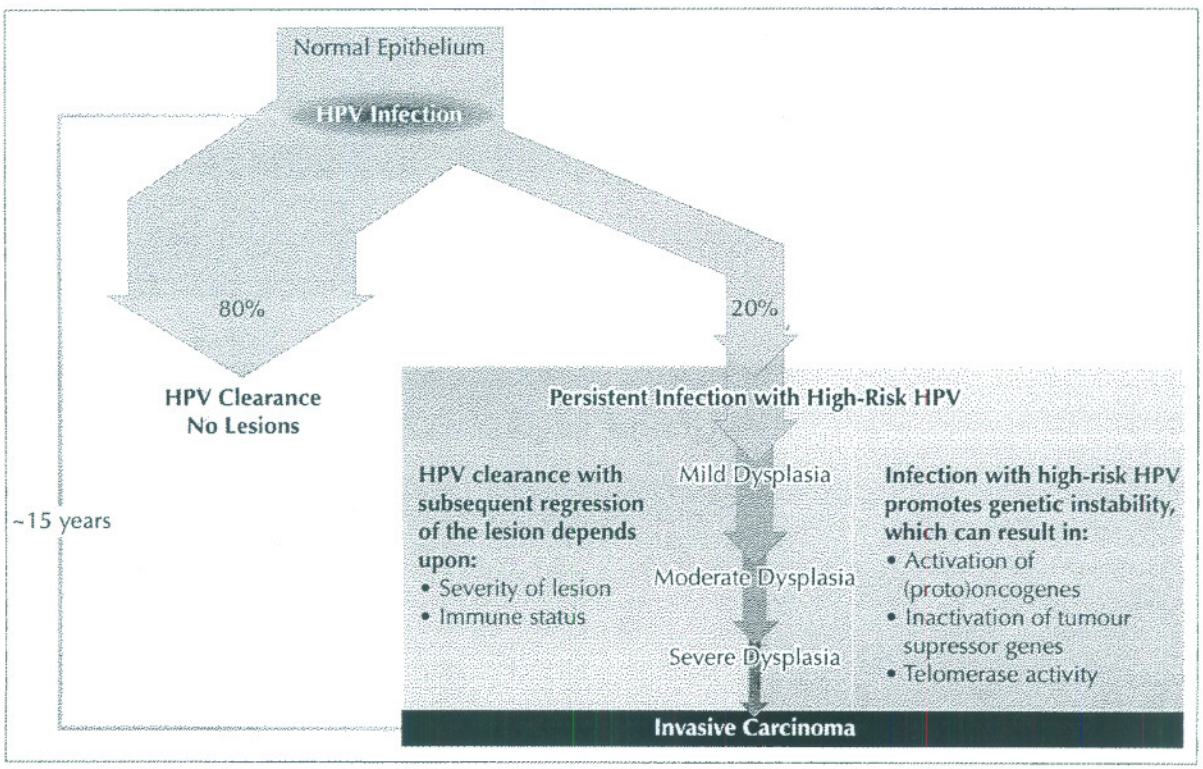
[3] Centers for Disease Control and Prevention (CDC), *Cancer Prevention and Control: Cervical Cancer Health Awareness,* May 10, 2005, http://www.cdc.gov/cancer/nbccedp/info-cc.thm (July 14, 2005).
[4] National Cancer Institute (NCI), *Cancer Facts: Human Papillomaviruses and Cancer,* May 17, 2005 *http://cis.nci.gov/fact/3_20.htm* (June 2, 2005).
[5] CDC, *Cancer Prevention and Control: Cervical Cancer Health Awareness, supra* note 25.
[6] Winer R, Lee S, Hughes J, Adam D, Kiviat N, Koutksy L. Genital human papillomavirus infection: incidence and risk factors in a cohort of female university students. Am J Epidemiol 2003;157:218-226.
[7] ACOG Practice Bulletin 61. April 2005. Human papillomavirus.
[8] Meijer CJLM, Snijders PJF, van den Burle AJC. Screening for cervical cancer: Should we test for infection with high-risk HPV. *Canadian Medical Association Journal* 2000;163(5):535-538.
[9] Freeman et al., *supra* note 2, page 13.
[10] Freeman et al., *supra* note 33.
[11] Ibid.
[12] CDC, *Cancer Prevention and Control: Cervical Cancer Health Awareness, supra* note 25.
[13] Waxman A. Human papillomavirus DNA testing in office practice. The Female Patient 2005; 30:28.

is present, there is no medical treatment to rid the body of the virus. The treatments provided are directed at addressing the precancerous conditions or genital warts resulting from HPV infection.

Figure 11[14]
HPV and Development of Cervical Cancer

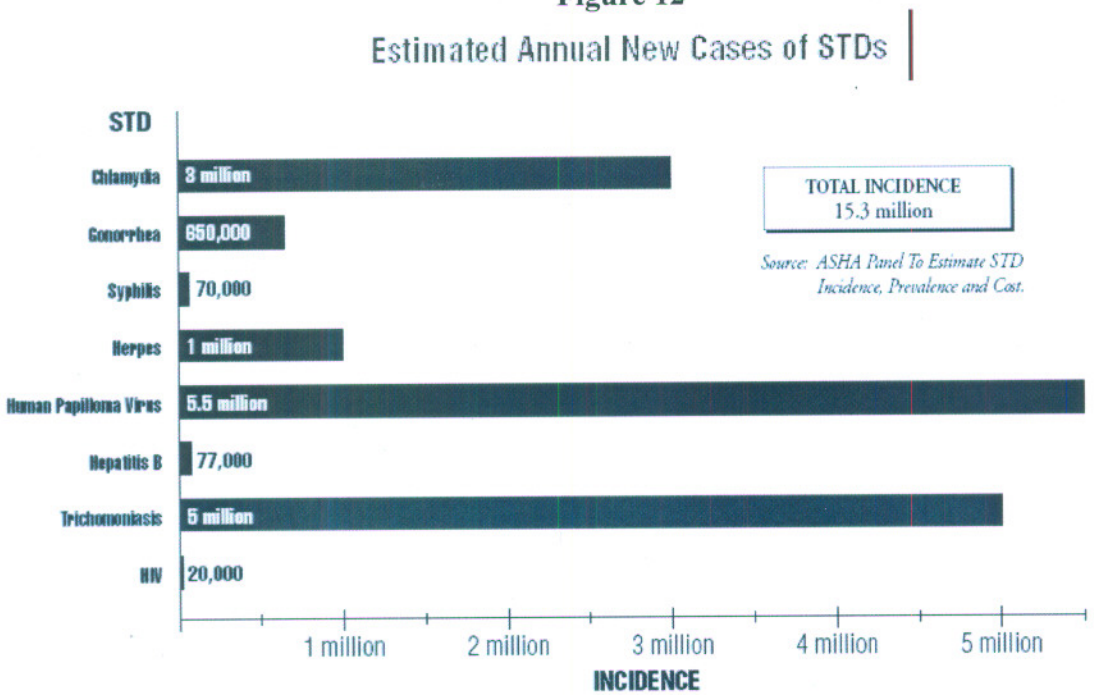


Source: *Canadian Medical Association Journal* 2000;163(5):535-538.

While cervical cancer mortality has declined due to early detection by Pap testing, management of cervical dysplasia caused by HPV causes considerable physical and psychological morbidity as well as considerable expense. [15] Figure 12 shows the estimated annual new cases and medical costs of HPV.

[14] Meijer et al., *supra* note 30.
[15] Yacobi et al., *supra* note 32.

Figure 12[16]



Estimated Annual Medical Costs of the Major Viral STDs in the United States

STD	Total Cost ($millions)
Genital Herpes	$208.0
HPV	1,622.8
Hepatitis B	51.4
HIV	4,540.0
Total costs, viral STDs	$6,422.2

All cost figures are adjusted to 1997 dollars using the Consumer Price Index, which includes medical expenses along with other consumer costs for urban consumers (approximately 87% of the U.S. population), from the U.S. Department of Labor's Bureau of Labor Statistics.

[16] Alexander, L.L., Cates, J.R., Herndon, N., Ratcliffe, J.F. December 1998. Prepared for the The Kaiser Foundation by the American Social Health Association. Sexually Transmitted Diseases in America: *How Many Cases and at What Cost?*

Public Knowledge of HPV

Nearly 87 percent of young men and women receive information about STIs through sex education classes offered in middle and high schools.[17] Epidemiological studies, however, show that the highest incidence of infection occurs in young adults between the ages of 18 and 28 and there is little evidence that young adults are aware of HPV infection of the genital tract.[18] For instance, several studies have shown men and women aged 20 to 24 years are not aware of HPV.[19] Specifically, one study found few were aware of an HPV infection of the cervix (29 percent of men and 35.3 percent of women), but the majority was aware of genital warts. Another study found young adults were unaware of the prevalence of HPV and lacked general knowledge of HPV infection, how HPV is transmitted and the relationship of HPV to cervical cancer.[20, 21] Other studies also have shown only a minority of college students are familiar with HPV and its complications.[22]

[17] Baer H, Allen S, Braun L. Knowledge of human papillomavirus infection among young adult men and women: implications for health education and research. *Journal of Community Health* 2000;25(1):67-78.
[18] Ibid.
[19] Lambert EC. College students' knowledge of human papillomavirus and effectiveness of a brief educational intervention. *The Journal of the Board of Family Practice* 2001;14(3):178-183
[20] Baer et al., *supra* note 44.
[21] Ibid.
[22] Lambert et al., *supra* note 46.

RISK FACTORS FOR CERVICAL CANCER

Relationship with Socioeconomic Status

According to Dr. Herschel Lawson, the medical officer of the CDC Division of Cancer Prevention and Control, data from health surveys show women least likely to have recommended cervical cancer screening are those with no health insurance and/or usual source of health care or are recent immigrants. Studies suggest these underserved women include those who are low income, have limited education, live in rural or inner-city areas, and are foreign born, are of racial/ethnic minority, and are older, disabled, uninsured, or underinsured.[23] "Reasons for not being screened vary considerably across these populations," Dr. Lawson said. "But efforts to identify and encourage these women to be screened requires culturally and community–sensitive education and methods to facilitate informed decision making about preventive health in general and cervical cancer screening specifically."[24]

Barriers to Care

Barriers to cervical cancer screening can be attributed to four factors:

1. **Income** - Women of lower socioeconomic status and those who lack health insurance are less likely to seek services.
2. **Age** – Older women of non-reproductive age are less likely to seek services.
3. **Perceptions and Beliefs** – Some women view screening to be unpleasant or uncomfortable, and believe screening will make them susceptible to cancer.
4. **Resources** – Women living in rural areas are less likely to have access to screening services and providers.

Barriers can be addressed by intensifying outreach to women who have rarely or never been screened for cervical cancer; increasing the number of female providers of the patient's race/ethnicity; improving coverage and reimbursement for cancer-related services; improving communication; and, research suggests, providing single-visit screenings and treatment for underserved women with high risk for no follow-up.

In some southern Illinois counties, family planning and screening services are not available. Therefore, women must make long commutes (up to two hours one way) to neighboring counties to access services. With no provider to screen in the local health departments or only a youth clinic that serves younger women up to age 20, women aged 20-34 do not have anywhere to obtain services. The Illinois Breast and Cervical Cancer Program's target population begins at age 35 for cervical screenings, but younger woman who are symptomatic can receive diagnostic services through the program.

[23] CDC, *Cancer Prevention and Control: Cervical Cancer Health Awareness, supra* note 25.
[24] Ibid

SCREENING, TREATMENT AND EDUCATION RESOURCES IN ILLINOIS FOR CERVICAL CANCER

Illinois Breast and Cervical Cancer Program

The Illinois Breast and Cervical Cancer Early Detection Program, which is administered by the Illinois Department of Public Health, began screening women in 1995 with funds obtained through the U.S.Centers for Disease Control and Prevention (CDC). The Illinois Breast and Cervical Cancer Program (IBCCP) annually receives more than $5 million in federal funding and $2 million in state General Revenue Funds to provide free breast and cervical cancer screening and follow up tests to women age 35-64, who reside in Illinois, are low-income and have no health insurance. The program works in partnership with 26 lead agencies located statewide and a network of 2,300 health care providers who perform clinical breast exams, mammograms, pelvic exams, Pap tests and diagnostic tests for enrolled women. To successfully reach and enroll high-risk women (e.g., women over the age of 50, never or rarely screened, geographically isolated and minority women), the agencies employ nurse case managers who serve as liaisons between the community and the health care system.

The CDC requires 75 percent of the women screened to be between 50 and 64 years of age; 25 percent of women screened may be between the ages of 35-49. CDC imposes these guidelines to ensure that women at greatest risk for breast and cervical cancer are screened. Since the Illinois Title X Family Planning program offers cervical screening to women of childbearing age, screening for women under the age of 35 was considered duplicative and not covered by the IBCCP. Research indicates that women over the age of 40 should have a screening mammogram every year and a Pap test every 1-3 years[25]. Grouping the breast and cervical screening exams together increases the probability women will receive these important health screens. The CDC program guidelines allow for states to screen women who earn up to 250 percent of the Federal Poverty Level (FPL), but Illinois chose to limit testing to women at 200 percent or below the FPL to conserve valuable screening resources for the women most in need.

The CDC requires any client with an abnormal cervical screening result to receive case management services. Once an abnormal result report is received, the IBCCP lead agency case manager uses an approved medical algorithm to determine further testing requirements. The case manager assesses the client's needs, creates an individual client plan to meet the identified needs, coordinates services needed to meet the plan, and then evaluates and monitors how the client's needs are met. Evaluation of case management efforts are gathered from the client data forms and reported as timeliness to treatment, timeliness of diagnosis and completed work-up. The IBCCP monitors any deviations from the accepted protocols and works with the IBCCP lead agency case managers to identify strategies to strengthen case management and ensure quality services are provided.

In fiscal year 2005, the IBCCP screened 17,600 unduplicated women, with 9,266 of those receiving cervical screenings. The Illinois Department of Healthcare and Family Services

[25] Saslow D, Runowicz CD, Solomon D, et al. American Cancer Society guideline for the early detection of cervical neoplasia and cancer. *CA Cancer J Clin*. 2002;52(6):342-62.

reports there are 630,000 uninsured women in Illinois and 346,187 of those are below 200 percent of the federal poverty level. Because the funding level has not increased, while program administrative expenditures and clinical care costs have increased, the IBCCP served only a fraction of the target population. Additional state or private funds would allow the program to close the gap between the number of women served and the unmet need. As a result of screening efforts in FY05, 170 cases of breast cancer, 24 cases of cervical cancer and 242 cases of cervical precancerous conditions were detected through the program.

To increase access to treatment, the federal Breast and Cervical Cancer Prevention and Treatment Act (BCCPTA) of 2000 created a unique optional Medicaid eligibility category for uninsured women screened under the CDC's National Breast and Cervical Cancer Early Detection Program and found to need treatment. This act established three options for defining eligibility:

Option 1: Women whose clinical services were provided all or in part by the CDC program;

Option 2: Women screened under a provider who receives CDC funds but whose clinical services are not paid for by CDC program; or

Option 3: Women who are screened by any provider that has been authorized by the state as a CDC grantee to provide screening activities.

Because of uncertainty and potential costs associated with the program at its inception in 1995, Illinois selected Option 2. As a result, in Illinois, women must have been diagnosed through the IBCCP in order to be eligible for treatment under Medicaid. Not all women screened will be eligible for this Medicaid covered group, including those who are undocumented and deemed eligible for another Medicaid covered group. The program currently has 405 women enrolled in Medicaid and receiving life-saving treatment services. However, if Option 3 were implemented, more women would qualify for treatment services under Medicaid.

Illinois Department of Human Services Title X - Family Planning

Illinois' Family Planning Program has been funded by federal dollars since 1970 and began receiving state funds in 1999. The program serves low-income women on a sliding fee scale and those who earn less than 100 percent of the federal poverty level are not charged for services.

The program is the seventh largest in the country, reaching 150,000 women last year. There are 54 lead agencies with 114 clinic sites. Reimbursement is based on Medicaid rates and paid on a fee for service with a cap award. Agencies are required to have other sources of funding, as well. Overall, clinical services provided by the Title X program exceed their current funding level by nearly $4 million.

Family planning services include cervical cancer screenings and HPV testing. Diagnostic work-up for abnormal Pap tests, including colposcopy and biopsy, are not provided due to lack

of funding. These younger symptomatic women are eligible to be referred to the IBCCP for appropriate diagnostic services, as is required under Option 2 (see previous section). In 2003, 4,783 women had precancerous cervical conditions.

Identified barriers to adequate care include the delay between initial contact and time to first appointment, which range from six weeks to one year.

While pockets of need have been identified, currently there is no funding available to expand to geographic areas where services are currently not provided. The average award per family planning client is $74 per woman, which is much less than cost to provide the care.

Penny Severns Breast, Cervical and Ovarian Cancer Research Fund

The Penny Severns Breast, Cervical and Ovarian Cancer Research Fund is a special fund within the state treasury that is used to award breast, cervical and ovarian cancer research grants. Revenue sources include general revenue funds, income tax contributions and gifts, as well as grants and awards from private foundations, nonprofit organizations and other governmental entities or persons. Grants support research in areas related to breast, cervical and ovarian cancer prevention, etiology, pathogenesis, early detection, treatment and behavioral sciences. Research also may include clinical trials. Although a majority of the applications submitted are bio-medical in nature, researchers in the fields of behavioral and social sciences also are encouraged to apply. The fund averages $250,000 a year in taxpayer contributions and receives an annual appropriation of $300,000 in state General Revenue Funds. Ovarian research was recently added and an additional $100,000 was appropriated for that purpose.

Illinois Department of Healthcare and Family Services – Healthy Woman & Medicaid

The Department of Healthcare and Family Services (HFS) serves 450,000 women aged 19-64 and 100,000 women over age 65 with its women's health services.

Illinois Healthy Women, which began April 19, 2004, provides family planning health care services/birth control to women who have recently lost regular HFS medical benefits. Family planning health care pays for birth control, physical exams and lab tests women need to plan their pregnancies. Women aged 19 through age 44 who leave the department's medical programs are offered enrollment in Illinois Healthy Women. The program makes it possible for these women to continue to obtain family planning and reproductive health care services from their regular physician. A woman also may choose to receive these services from any other Medicaid-enrolled provider of family planning services.

HFS administers the Breast and Cervical Cancer Eligibility Unit (BCCEU) which covers women who need treatment for breast and cervical cancer when directly referred through IBCCP. Health benefits are only available to women screened or diagnosed through IBCCP and in need of treatment for breast or cervical cancer or a precancerous condition. Women diagnosed with breast or cervical cancer through their private physician or through another program are not eligible for services. The process to determine eligibility for enrollment in the Health Benefits

for Persons with Breast or Cervical Cancer Program is a cooperative endeavor between HFS' Breast and Cervical Cancer Eligibility Unit and IBCCP staff. HFS must confirm potential clients are U.S. citizens or meet immigration requirements and are uninsured. The costs of medical services for these women are eligible for federal reimbursement at an enhanced rate of 65 percent.

LIMITATIONS IN COVERAGE OF EXISTING PROGRAMS

Despite the state and federally funded programs described above, many women still do not qualify or are unaware programs that provide cervical cancer screenings exist. The role of Medicaid for non-elderly adults is limited, covering some parents and low income disabled individuals, but most adults without dependent children – regardless how poor – remain ineligible for Medicaid. While most Americans point to the importance of Medicaid, and many have a basic understanding of this complex program, about half tend to be less familiar with the program's specific details. More than half (53%) do not know that Medicaid is the insurance program for many low-income families regardless of their age[26]. Additionally, those receiving Medicaid funds may have high spend-downs, similar to insurance deductibles, which prohibit them from getting the needed cervical screenings.

The uninsured are predominantly adults from low-income working families. Over 80 percent of the uninsured come from families with a full-time or part-time worker and nearly two-thirds come from low-income families (less than $30,000 for a family of three). Unfortunately, the remaining one-third makes slightly over the 200 percent of federal poverty level and does not qualify for many subsidized programs. In addition, those at the highest risk of being uninsured include the poor, young adults, minorities, and non-citizens. While Medicaid and the State Children's Health Insurance Program (SCHIP) have expanded in recent years to cover more children, public coverage for adults is limited. Among the non-elderly, the chances of experiencing a long spell without health insurance (12 months or longer) are highest for individuals with low incomes and young adults[27], those at greatest risk of developing cervical cancer.

Publicly funded family planning clinics are an important source of contraceptive and other reproductive health care, providing nearly 150,000 Illinois women with a wide range of services. Unfortunately, these services are not available in every geographic area throughout the state, and many clinics may be financially challenged in their efforts to continue delivering this broad package of services to growing numbers of uninsured or disenfranchised women. Additionally, in rural communities, the lack of providers participating in family planning programs results in these services simply being unavailable.

[26] The Kaiser Commission on Medicaid and the Uninsured. http://kff.org/uninsured/upload/Covering-the-Uninsured-Growing-Need-Strained-Resources-Fact-Sheet.pdf
[27] Kaiser Family Foundation, http://www.kff.org/uninsured/7155.cfm

DEVELOPMENT OF PREVENTION PLAN

To date, the task force's action plan has focused on prevention and education to raise awareness about the importance of screenings and follow-up treatment. The intended target groups mirrored those of CDC's HPV Two-Year Communication Plan:

1) General public;

2) Health care providers; and

3) Patients and their partners.

The task force has done a thorough study of racial, ethnic and cultural disparities to identify causes and develop a plan to address findings. This aligns with the National Cancer Institute's recommendation to "Conduct social/behavioral health services and intervention research to better understand high-risk populations to improve their care."

In Illinois, there are substantial disparities between African-American women and white women for cervical cancer incidence, mortality and staging of diagnosis. The disparity is similar for Hispanic women. National data also suggest disparities exist in the Asian population when compared to white women. It is also likely that undocumented, ethnic and minority populations present unique challenges. In order to best target such populations, the cultural and social issues must be understood.

The task force also has identified areas of the state where lack of services makes it difficult for women receiving screening services. Additional funding is recommended to develop and enhance programs to provide cervical cancer screening; further diagnostic testing, such as repeat Pap testing, colposcopy and/or HPV/DNA testing; and management services for precancerous conditions and cervical cancer. Women should not have the added burden to travel long distances for treatment or to have procedures associated with resolving precancerous conditions. Additional barriers to women actively addressing this health issue involve time and expense, especially for women who do not qualify for the Illinois Breast and Cervical Cancer Program. This recommendation concurs with National Cancer Institute's Center to Reduce Cancer Health Disparities suggestion to "improve coverage and reimbursement for cancer-related services" and "intensify outreach to women who have rarely or never been screened for cervical, breast or colon cancer and screenable/treatable diseases."

Other discussions by the task force dealt with issues related to insurance coverage for cervical cancer. Legislation requires all group insurance policies, except specified disease policies, limited benefit policies, and individual and group HMO contracts, to cover annual cervical Pap tests. Self-funded companies do not have to comply with state mandates and, therefore, may choose not to cover these services, leaving many women inadequately covered for cervical cancer screening services. To increase awareness of policy plan limits, House Bill 0500 creates the Illinois Consumer Choice of Benefits Health Insurance Plan Act, which allows

insurers to offer policies of accident and health insurance that do not provide state-mandated health benefits while requiring applications and policies to contain notice that the policy may not cover some or all of the state-mandated health benefits. For those with health care coverage, physicians often underscreen for cervical cancer regardless of insurance companies efforts to provide information to providers to increase screening for cervical cancer. The most common reason women give to explain why they did not receive regular Pap tests is that the doctor did not recommend the test. It is important for providers to recommend to their clients the need for cervical cancer screening. Finally, certain eligible Illinois residents have been denied major medical coverage by private insurers because of their health status. For them, the Illinois Comprehensive Insurance Plan (ICHIP) provides access to coverage.

Medicaid Status and Coverage of Reproductive Health Care

The Illinois Department of Healthcare and Family Services (HFS) monitors cervical cancer screening among other maternal and child health outcome measures for women enrolled in its medical programs. The data is sorted by state, county and by each contracting managed care organization (MCO). The data is derived from HFS' Medical Management Information System and is based on paid fee-for services (FFS) or managed care encounter data. The criteria used for this measure is based on the National Committee for Quality Assurance's (NCQA) HEDIS (Health Plan Employer Data and Information Set) guidelines, a set of standardized performance measures for managed health care plans. The performance measures in HEDIS are related to many public health issues important to prevention and wellness. One measure is the percentage of women 18 to 64 years of age who received one or more Pap tests in the previous year or two years. Health plans whose products are accredited by the National Committee for Quality Assurance (NCQA) report HEDIS data. In addition, many plans report HEDIS-like data for non-accredited products.

HFS includes women who were continuously enrolled during the measurement year, but excludes women whom the Department has claims or encounter data showing hysterectomy with no residual cervix.

Table 3 illustrates that less than 50 percent of women eligible for free or low cost screenings are actually getting screenings. The table depicts the percentage of HFS women aged 21-64 who have received one (or more) Pap tests during the reporting year or the two years prior to the reporting year, excluding women who are identified as having had a hysterectomy with no residual cervix.

Illinois Department of Healthcare and Family Services
Coverage of Reproductive Health Care
Table 3[28]

State Total	CY 2003	CY 2004	CY 2005
FFS + MCO	44.90%	47.30%	45.92%

State Total	CY 2003	CY 2004	CY 2005
FFS Only	45.63%	47.55%	45.91%

MCO Data	CY 2003	CY 2004	CY 2005
Amerigroup	28.71%	36.94%	41.76%
FHN	37.80%	44.28%	47.05%
Harmony Cook	16.13%	27.72%	35.45%
Harmony Downstate	38.22%	46.80%	37.29%

Health Insurance Status and Coverage of Reproductive Health Care

A 1997 survey by the Kaiser Foundation found 82 percent of women surveyed had health insurance and 69 percent report they were covered, at least in part, for routine gynecological care. Women who do not have health insurance were less likely than insured women to have a regular gynecological care provider (72% versus 88%) and to get a gynecological examination at least once a year (67% versus 76%).[29]

The survey also reported younger women are less likely to have health insurance with only about three-quarters of women ages 18 to 29 who were surveyed (77%) having health insurance as compared to 85 percent of women age 30 to 39 and 87 percent of women age 40 to 44.

Typical health insurance coverage of reproductive health care includes a gynecological checkup. Virtually all health maintenance organizations (HMOs) (99%) routinely cover an annual gynecological exam, but only 88 percent of point-of-service (POS) networks, 64 percent of preferred provider organizations (PPOs) and 49 percent of indemnity plans do. All HMOs and virtually all POS networks provide at least some coverage of pap smears and chlamydia cultures, but not all indemnity plans or PPOs do. Almost all HMOs and POS networks routinely cover mammograms for women older than 50, while only eight out 10 PPOs and indemnity plans do.[30]

This implies that regardless of coverage, women need education about the importance of regular Pap tests. Evidence shows reminders are an effective way to increase the use of preventive services and health care providers need to implement reminder systems to increase utilization of screening services.

[28] Illinois Department of Healthcare and Family Services, Feb. 2006.
[29] Survey of Women About Their Knowledge, Attitudes, and Practices Regarding Their Reproductive Health Glamour; Kaiser Family Foundation; Princeton Survey Research Associates, February 1997
[30] 1993 Alan Guttmacher Institute survey on reproductive health care coverage, *Improving the Fit.*

Task Force Activities and Recommendations:

In an effort to begin development of a Prevention Plan and recommend strategies or actions to reduce the occurrence of cervical cancer as outlined in Public Act 093-0956, it was decided that two sub-groups (professional and consumer) be formed to focus the initial awareness campaign efforts. The following members serve on the sub-groups:

PROFESSIONAL	CONSUMER
Dr. L. Stewart Massad, Co-Chair	Dr. Yvonne Collins, Co-Chair
Dr. Sydney Ross-Davis, Co-Chair	Maria S. Pesqueira, Co-Chair
Dr. Stanley Borg	Elizabeth S.A. Patton
Stephani Huston Cox	Ray Valek
Dr. Carol Wilson Saffold	Gwendolyn West
Dr. Quincy Scott, Jr.	Linda Wheal
Pamela W. Balmer, Staff	Jean Becker, Staff
Jean Becker, Staff	Jan Costello, Staff
Christine Carver, Staff	

To address strategies to reach southern counties with high incidence rates, the following reasons were identified for why women did not receive screenings: money, lack of providers, transportation and culture. It also was noted that providers do not encourage women to be screened and often are not properly using screening strategies, thereby affecting treatment plans.

Professional ***(Co-Chairs: Drs. Massad and Ross-Davis)***

The Professional Sub-committee members developed and completed a survey to guide them in developing a plan for outreach to providers as part of the cervical cancer elimination effort in Illinois. Targeted themes to be considered in the plan were:

1. Education of and outreach to providers – Who, how and in what format is yet to be decided. A list of professional organizations has been collected for consideration. A speakers' bureau has been suggested. The professional sub-committee will await the publishing of industry-sponsored power point presentation that could be utilized for this purpose. It must be reviewed before a final decision is made.
2. Increase involvement of the local health departments in programs to screen women and obtain follow-up services.
3. Use of a reminder system (electronic or other) within providers offices to encourage women to return for Pap tests.
4. Identification of methods to locate providers who treat women who are rarely or never screened needs further consideration.

Specific recommendations included:

1. A letter, signed by Dr. Whitaker, should be sent to provider organizations to solicit input on how best to reach clinicians who provide screening and cancer prevention services in Illinois. The sub-committee has developed a draft letter that recommends

the Director encourage provider organizations to send to their members emphasizing the importance of screening and treatment for this preventable cancer.

2. The Director should send a second letter to the deans of medical schools that train clinicians asking them to report on curricula used to teach cervical cancer screening and prevention measures.

3. Legislators should consider mandating patient notification of the results of Pap results as is required after mammography. The goal of this recommendation is to minimize loss to follow-up, a distinct problem the management of cervical cancer precursors.

4. Task force members should develop a speaker network to provide provider education to clinicians, especially those in areas identified as having high rates of cervical cancer mortality. Collaboration with the faculty of state-supported schools may be useful in this regard.

5. Consider the creation of state incentives to foster the use of electronic reminder systems that, in turn, will maximize timely screening.

6. Educate legislators and staff from areas identified by state epidemiology staff as having disproportionately high rates of cervical cancer. Educational messages may include highlighting the scope of the cancer burden among their constituents and developing outreach to providers using specific local resources to maximize coordination between existing private and public services.

Consumer ***(Co-Chairs: Dr. Collins & Ms. Pesqueira)***

The Consumer Sub-committee made recommendations to implement a public health education campaign to address the prevention of cervical cancer and HPV with priority given to geographic hot spots in the state and Chicago. Reaching all at-risk populations requires mass media techniques, including paid television advertising, as well as direct mail to individuals in state hot spots. Mass media can be supplemented by grassroots advocacy and statewide and local public relations efforts focused on gaining free media coverage. These public relations efforts would include developing strong story platforms based on clinical data and/or consumer/provider attitudes, creating a statewide network of experts who could speak knowledgeably about cervical cancer prevention and writing a series of news releases and articles. Grassroots advocacy efforts could include peer mentoring programs and screening guideline communication.

Knowledge gained from a public education campaign might lead to primary prevention of HPV infection and, thus, prevention of precancerous conditions and cervical cancer. Additionally, cervical cancer screening rates may be impacted.

Many national, reputable resources and campaigns have been developed to address these issues. Current research shows the general public lacks a fundamental understanding about HPV, as well as its role in the development of cervical cancer. In addition to statistics already discussed, findings from a recent survey conducted by the Association of Reproductive Health

Professions found only 23 percent of women surveyed understood HPV was the primary cause of cervical cancer and less than one third of women have talked about HPV with their doctor.[31]

The recommendation to implement a public health education campaign aligns with the NCI recommendation to "improve awareness and knowledge about cervical cancer through the development and provision of linguistically and culturally appropriate information" and to "intensify outreach to women who have rarely or never been screened for cervical, breast, or colon cancer and other screenable/treatable diseases."

Additional recommendations include:

1. Identify and partner with other screening programs in the state.
2. Encourage legislators to stay involved with the fight.
3. Identify the patterns of screening, follow-up and treatment for women.
4. Identify other educational avenues (i.e., school systems, including adding cervical cancer education to health education materials; libraries; YMCA or YWCA).
5. Build relationships with those working in underrepresented communities to eliminate attitudinal and cultural barriers to care.
6. Ally with those in the community to speak with others in their communities on cervical cancer prevention.
7. Write and submit an article on cervical cancer to community papers where women are effected.
8. Develop public service announcements on the importance of cervical cancer screening and the ability to prevent the disease.
9. Develop media tool kits for local public health workers.
10. Encourage relevant state agencies to work with insurers to develop systems for reporting rates of cervical cancer screening modeled after the national HEDIS program and then develop strategies to improve screening rates among insured women.

In summation, the Cervical Cancer Elimination Task Force realize we are in the beginning stages of outlining recommendations and developing a final plan. The task force remains steadfast and committed to the work at hand. We are fortunate enough to live in an era in which women should not be dying from cervical cancer. The single most important thing a woman can do is to participate in a regular screening program. Women who are screened enjoy a dramatic reduction in the risk of cervical cancer compared to women who do not since precancerous lesions can be detected and treated early. Cervical cancer is preventable. Let's educate women so that no more women needlessly die.

[31] Survey reveals women and doctors aren't talking about HPV. Association of Reproductive Health Professionals. Association of Reproductive Health Professional. Press Release June 28, 2005.

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