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The Invisible People with Cancer Are Least Likely to Get Quality Care *Group Issues Agenda-Setting Report to Identify, Help Americans Who Are Falling Through the Cracks*

April 3, 2008; Washington, DC -- With mounting evidence that many Americans remain the invisible people with cancer who don't get regular screening examinations, smoke at higher rates, are frequently diagnosed after their cancer has spread and, therefore, die more frequently and more quickly from this disease, the Intercultural Cancer Council Caucus (ICCC) today issued a 12-step action plan outlining how the Administration and the U.S. Congress can begin to help those cancer patients who are falling through the cracks of the healthcare system.

In conjunction with ICC's 11th Biennial Symposium on Minorities, the Medically Underserved, & Cancer held in Washington, DC, the ICC Caucus released a new report -- *From Awareness to Action: A Renewed Call to Eliminate the Unequal Burden of Cancer* -- that provides realistic goals for helping racial and ethnic minorities, those living in rural areas, the elderly and the poor who remain at greatest risk for developing and dying from cancer. Issued as a nationwide call to action, the report states that unless more is done to address the unequal burden of cancer faced by ethnic minorities, the elderly and the poor, "disparities in cancer care will only increase over the next half-century."

The new report, designed to provide the most up-to-date information about disparities in cancer rates and death among the nation's medically underserved, finds that certain Americans remain largely invisible to the healthcare system and are the least likely to have access to quality cancer care at all points in the process -- from screenings and diagnosis to access to state-of-the-art cancer therapies and end-of-life palliative care. Specifically, the report reveals a widening gap in cancer care among American Indians and Alaskan Natives and those living in the out islands of Hawaii, Guam, Samoa and other Pacific Islands, who now have cancer incidence and death rates similar to third world countries. The report also finds that many poor whites have cancer diagnosis rates as high as or higher than those for ethnic minority groups most affected by the disease.

"As the nation considers reforms to the health care system, no workable agenda can ignore the pressing issue of combating disparities in cancer care," said Lovell A. Jones, Ph.D., co-founder of the ICC. "An intensified focus on providing quality cancer care for all Americans is essential to winning the war against cancer."

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Looking specifically at those populations that are the least likely to benefit from the nation's overall decrease in cancer deaths, the report finds the unequal burden is highest among African Americans, where cancer deaths are 35 percent higher in black men and 18 percent higher in African American women than in the general population. However, Native Hawaiians now have the second highest overall rate of cancer in the U.S., the highest death rates for stomach cancer, and the highest incidence and death rates for endometrial cancers. Moreover, American Samoans have a higher relative risk for cancers of the nasopharynx (especially men), stomach, liver, lung (especially men), uterus, thyroid and blood while all the Pacific jurisdictions (Republic of Palau, Guam, American Samoa, Republic of the Marshall Islands and the Commonwealth of the Northern Marianas) except the Federated States of Micronesia list cancer as one of the top three causes of death.

Among the 4.3 million American Indians and Alaska Natives now living in over 560 federally recognized tribes and over 100 state-recognized tribes, the report finds that cancer rates, which were previously reported to be lower in these individuals, have been increasing in the past 20 years. As a result, cancer is now the second leading cause of death in American Indians and Alaska Natives and incidence and death rates from kidney cancer in these populations is higher than for any other racial or ethnic population. Further, lung cancer is now the most common type of cancer death in eight of the nine Indian Health Service (IHS) Areas.

Also classified as the invisible people with cancer are the rural, poor whites living in regions like the Appalachian Mountains where the economic status of 78 counties have been designated as "distressed" and another 78 counties are considered "at risk." Here, the report finds cancer incidence rates are higher in Appalachia than the rest of the U.S. and the rates for lung, colorectal, and other tobacco-related cancers are particularly high. Further, cervical cancer death rates for the Appalachian regions of three states (Kentucky, Ohio, and West Virginia) are much greater than the overall U.S. cervical cancer death rate.

According to the ICCC's assessment, poverty is the major factor contributing to higher cancer incidence and mortality rates among the medically underserved. The report finds that smoking is especially prevalent among those who are poor (34.7 percent) and nearly poor (34.2 percent). Further, the report finds that although smoking rates between African Americans (25.9 percent) and whites (25.9 percent) are not significantly different, black Americans are more likely to suffer smoking-related mortality, due in part to the increased smoking of menthol cigarettes, which are more addictive.

What is equally disturbing, according to the new report, is that minorities and the poor are less likely to be screened for cancer and, therefore, are more likely to have late-stage cancer when the disease is diagnosed. Here, the review finds that only 66 percent of American Indian/Alaska Native women 60 years or older have ever had a breast exam and only 36.5 percent of Hispanic women aged 50 plus have regular screening mammograms. At the same time, the report reveals that Asian American, Hispanic, low income and less educated women are less likely than the general population to get Pap smears, greatly increasing their risk of being diagnosed with invasive cervical cancer.

According to the report, a major factor behind these disparities is the prevailing societal and institutional racism. While overt racism is seldom practiced or observed in today's medical setting, the report finds that a "deep-rooted institutional memory of racism" permeates the nation's health policies and practices, as well as in the personal attitudes and perceptions of health care providers and researchers.

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Also addressed in the report is access to pain management and palliative care at the end of life, two areas where disparities in cancer care are significant. Specifically, the ICCC review finds that metastatic cancer patients at centers that treat predominantly minorities are three times more likely than those treated elsewhere to have inadequate pain management. The report further shows that research in cultural quality-of-life issues, including pain symptom management, has been neglected. Most pain literature acknowledges that culture influences cancer pain management, yet little empirical work has been conducted in this area.

To begin to change these statistics, the ICC Caucus has created a 12-point action plan to provide vulnerable populations with greater access to programs that will prevent, detect and treat cancer at its earliest stages while supporting these individuals through and beyond treatment. Specifically, the organization is calling on the Administration and the U.S. Congress to take immediate action in these areas:

1. Fully implement and fund the recommendations of the Trans-DHHS Cancer Health Disparities Progress Review Group, *Making Cancer Health Disparities History*. This report contains 14 recommendations that will mobilize the government's available resources to eliminate cancer disparities.
2. Fully fund the Patient Navigator, Outreach and Chronic Disease Prevention Act of 2005, which was signed into law with strong bipartisan support from Congress, but has yet to be funded and has a sunset looming over its ability to be implemented.
3. Enhance the collection of data that will better describe racial, ethnic and socioeconomic diversity in cancer care in the U.S.
4. Increase federal funding for government programs that provide greater access to cancer screening programs.
5. Acknowledge and then move quickly to fully address and monitor institutionalized racism as a major factor in the excess burden of cancer borne by our nation's minority and medically underserved communities.
6. Make tobacco control a priority concern, backed by new federal and state initiatives that are specifically targeted to minorities and the medically underserved.
7. Eliminate the barriers to more effective pain management and palliative care for minorities and the medically underserved.
8. Increase the level of knowledge about cancer survivorship among the medically underserved.
9. Restore Medicare reimbursement for cancer treatment and cancer care in all settings this year.
10. Immediately implement and increase the funding for the Medicare demonstration project providing access to oral chemotherapy drugs.
11. Enact the Patients' Bill of Rights to provide strong comprehensive protection to all cancer patients in managed care plans.
12. Achieve universal health insurance and establish a schedule to reach this goal by 2010.

“Creating a public policy agenda that focuses on eliminating the disparities in cancer care must occur immediately if we are going to eliminate the unequal burden of cancer experienced by minorities and the poor,” concluded Jennie R. Cook, President of the ICC Caucus. “The action plan advocated by the ICC Caucus will make the difference in the lives of many Americans.”

The Intercultural Cancer Council Caucus is an advocacy organization whose mission is to advance policies, programs, partnerships and research to eliminate the unequal burden of cancer among racial and ethnic minorities and medically underserved populations.

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