

Closing the Gap

A newsletter of the Office of Minority Health, U.S. Department of Health and Human Services



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Lifting the Unequal Burden of Cancer on Minorities and the Underserved

NCI Develops Strategic Plan to Reduce Cancer-Related Health Disparities

By Houkje Ross

The National Cancer Institute (NCI) recently unveiled a major new effort to identify and address the underlying causes of cancer-related disease and disability in racial and ethnic minority and underserved communities throughout the country. As part of this effort, NCI appointed renowned cancer researcher Harold P. Freeman, MD, as associate director for reducing health disparities. Dr. Freeman will ensure implementation of a strategic plan, released in May 2000, which aims to improve efforts to understand and reduce the cancer disparities seen in many minority and underserved populations.

"Addressing the unequal burden of cancer has never been more important," said NCI Director Richard Klausner, MD, in announcing the Freeman appointment. National data and reports from the Institute of Medicine (IOM), NCI, and other sources document the extent of the problem.

This year, the American Cancer Society (ACS) estimates that over 1.2 million cases of cancer will be diagnosed. The disease is now the second leading cause of death among Americans and is expected to creep up to number one, according to NCI. Many racial and ethnic minorities, and other medically underserved groups are more vulnerable to the disease, and some forms of cancer are seen at much higher rates in these populations.

For example, although the rate of breast cancer in African Americans is not as high as in white women, African American women are more likely to die from the disease once it is detected. Hispanic and Vietnamese women have some of the highest rates of cervical cancer, while many American Indians experience the lowest survival rates of any other population.

Some disparities can be explained by late diagnosis, lifestyle factors, and access to health care. But researchers still need to be asking the right questions when it comes to certain ethnic and minority groups, said Moon Chen, PhD, professor and chair of the College of Medicine and Public Health, Ohio State University. "Like why do smoking rates increase for Asian American women the longer they have been in this country, but the rates go down for Asian American men?" Dr. Chen asked. The NCI strategic plan will help answer these types of questions.

NCI's plan to improve programs for minorities and the medically underserved



Harold P. Freeman, MD, named NCI Associate Director for Reducing Health Disparities.

Part of the National Institutes of Health, NCI carries out research on the prevention, detection, treatment, and control of cancer. NCI's strategic plan to reduce cancer health disparities follows thoughtful review of the IOM report, *The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Minorities and the Medically Underserved*. The report reviewed programs within NCI that specifically target minorities and other medically underserved groups. The report made recommendations to NCI as to where the agency could improve its efforts in understanding the causes of health disparities in cancer.

NCI's response, the *Strategic Plan to Reduce Health Disparities*, sets objectives in five major areas, including expanding research on the determinants of cancer-related disparities; expanding capacity to define and monitor these disparities; strengthening research on prevention, early detection, treatment and communications; improving research

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dissemination and collaborations that will translate research into practice; and strengthening professional education and training, and working to increase the numbers of minority scientists.

Some of the specific initiatives included in the NCI plan are:

- **Expand the Surveillance, Epidemiology and End Results (SEER) Program.** NCI will expand SEER to include populations that are currently underrepresented. These include non-Mexican Hispanics, rural African Americans, and American Indians. If feasible, NCI will also provide technical assistance and training to non-SEER population-based registries.
- **Expand cancer communications survey research.** NCI will conduct a biennial Health Information National Trends Survey (HINTS) of a nationally representative sample of the United States, with underserved populations over-sampled. This will help identify the cancer information seeking strategies and needs of the American public. HINTS will be the first nationally representative longitudinal analysis of the public's access to and use of health information. The survey will provide a clear picture of both current and emerging trends in cancer information seeking practices, needs, channel utilization, channel preferences, and source preferences.
- **Redesign the clinical trials system.** NCI will improve its efforts to recruit and retain minorities, underserved populations, and the elderly in clinical trials and tailor its approaches to address linguistic and cultural differences so that interventions developed can be applied to sub-populations.
- **Increase collaborations with minority professional organizations.** The NCI and the National Medical Association (NMA) have a successful collaboration to increase participation of minority medical professionals in NCI-sponsored clinical trials. NCI will aim to increase both the number of NMA physicians involved in the current collaboration and the dialogue with Hispanic, Asian, and other professional groups.
- **Strengthen training in minority colleges and universities.** NCI will facilitate participation of minority students and faculty of minority schools, support promising young minority high school and undergraduate minority students, and attract underrepresented minorities into cancer-related research activities.
- **Develop special partnerships.** This initiative will model how to best reduce health dispari-

ties in underserved communities through research dissemination and diffusion. A partnership program with the ACS and Centers for Disease Control and Prevention (CDC) will focus on community-based needs assessment, and how to set priorities for program implementation based on local needs, inter-vention evidence, and local resources. Special partnerships will be developed with local and regional public health organizations to help develop the program.

- **Other initiatives.** NCI has recently developed the Expanded Participation Project and the Special Populations Networks (see p. 12).

Overseeing implementation will be Dr. Freeman, currently chairman of the President's Cancer Panel, a three member board that reports directly to the President of the United States. Known as one of the first scientists to point out the relationships between race, poverty, and cancer, Dr. Freeman is a past President of the ACS, and for 25 years was director of surgery at New York's Harlem Hospital before taking his current post as president and CEO and director of surgery at North General Hospital in New York City. (Dr. Freeman is interviewed on p. 5.)

Armin Weinberg, PhD, former chair of the Intercultural Cancer Council (ICC), a multicultural coalition that helped promote the initiation of the IOM study, said he is optimistic about NCI's plan, especially if the institute does a good job of monitoring it. "NCI has made significant changes in its infrastructure and has taken major steps to be responsive to the IOM report," said Dr. Weinberg. "The ICC stands ready to work with and give input to NCI on its goals to better understand cancer disparities."

"We also look forward to working with the CDC, Health Resources and Services Administration, and the Office of Minority Health to improve education, outreach, access, research, and training to help those organizations fulfill their missions while we fulfill ours," Dr. Weinberg said. (For more on the ICC, see story on p. 5).

"NCI has taken the IOM report very seriously and we are starting to see benefits from it," said Dr. Chen.

To obtain the full strategic plan, contact Susan Sieber, director of communications, NCI (301) 443-5946, or view it on Web: <http://www.nci.nih.gov/announcements/healthdisprpt.pdf>. NCI invites comments on the strategic plan. ❖

Working Together to Better Understand Cancer-Related Health Disparities

Editorial by Nathan Stinson, Jr., PhD, MD, MPH

Deputy Assistant Secretary for Minority Health, U.S. Department of Health and Human Services

Cancer. More and more Americans are surviving it than ever before, thanks to scientific advances in cancer research and technology. Yet despite these gains, cancer mortality and morbidity rates have in some cases increased for minorities, while declining or remaining stable for Whites. These inequities in cancer statistics beg the question: do *all* Americans have access to and benefit from these progressions in our understanding of cancer?

Historically, minorities have been underrepresented in all phases of the biomedical research process. Systems for data collection and reporting with respect to minorities are uneven and sometimes outdated. Moreover, minorities have traditionally been overlooked both in planning and implementing biomedical and health related research, including epidemiological, behavioral, and community-based research and clinical trials. Nor have minorities been included in adequate numbers to provide statistically valid estimates of health outcomes and differences, if they exist.

A recent Institute of Medicine (IOM) study, *The Unequal Burden of Cancer*, took a critical look at the National Cancer Institute's (NCI) programs targeting minorities and the medically underserved. The study found areas for improvement, citing that minorities and the poor are underrepresented in NCI-funded research.

NCI responded with a comprehensive strategic plan to eliminate cancer-related health disparities (see story on p. 1). The recent naming of Dr. Harold Freeman to lead this effort will further propel NCI toward achieving its goal. Dr. Freeman has dedicated much of his career to examining health issues that affect minorities and the poor. By choosing Dr. Freeman to oversee its strategic plan, NCI is showing a strong commitment to eliminating the gaps in cancer incidence and mortality.

The Centers for Disease Control and Prevention's (CDC) National Program of Cancer Registries (NPCR), is a fundamental component of the CDC's vision for a dynamic state-based cancer control strategy. The CDC supports registries in 45 states, the District of Columbia, and three U.S. territories, representing 96 percent of the U.S. population. NCI's Surveillance, Epidemiology and End Results (SEER) program collects cancer incidence data in the remaining five states.

Cancer surveillance serves as the foundation for a national, comprehensive strategy to reduce illness and death from cancer.

Such surveillance is an indispensable tool that enables public health professionals at national, state, and local levels to better understand and address the cancer burden while advancing clinical, epidemiologic, and health services research. We must continue to support these efforts because, without sufficient data on minorities, we will not be able to fully determine the health needs and trends reflective of our communities.

The American Cancer Society (ACS) has recently awarded grants totaling nearly \$5 million toward studies that specifically address cancer among poor and underserved populations. The funding is in addition to the millions ACS already spends on research affecting these populations (see story on p. 12).

The Intercultural Cancer Council (ICC) is an organization that has been in the forefront of the fight against cancer in minority and underserved populations. It was the ICC's efforts that helped lead the charge for the IOM study. In addition, the ICC has been involved with the *Healthy People 2010* work group on cancer, further investing its efforts in the fight against cancer in minorities and the underserved.

The ICC reflects a true success story. The ICC has proven to us all that people can come together from all different walks of life and can speak with one voice against the disproportionate impact of cancer in minority and medically underserved communities.

We must all continue to pull together in our commitment to fight cancer. The U.S. Department of Health and Human Services has been taking a stronger, more visible approach to reducing and eventually eliminating health disparities in six areas of health, including cancer screening and management, through the Initiative to Eliminate Racial and Ethnic Disparities in Health.

As part of the initiative, the Office of Minority Health is responsible for maintaining the Race and Health Web Site, the Department's official Web site for the initiative. Please browse the site to learn more about our effort to eliminate health disparities in cancer and other illnesses that burden our communities.

For more information on cancer, visit the Race and Health Web Site: <http://www.raceandhealth.omhrc.gov>, and click on cancer screening and management. ❖

Do all Americans have access to and benefit from these progressions in our understanding of cancer?

Lay Health Workers Can Help Change Behaviors

By Houkje Ross

Involving community lay health workers in education about the need for cervical cancer screening can be a successful way to reach minority populations. A recent study by the Vietnamese Community Health Promotion Project at the University of California at San Francisco (UCSF), shows a huge leap in cervical cancer screening among recent immigrants from Vietnam who participated in the study.

The results of the study, *Opening Pathways to Cancer Screenings for Vietnamese-American Women: Lay Health Workers Hold the Key*, show a jump in cervical cancer screening among recent immigrants from Vietnam who participated in the study. The percentage of women who had ever heard of a Pap smear more than tripled, from 22 to 78 percent. The percentage of women who had ever had a Pap smear rose from 46 to 66 percent; and those women who maintained or continued to receive a Pap smear increased from 26 to 45 percent.

High rates of the disease coupled with limited knowledge of prevention and treatment make cervical cancer a serious threat to the health of Vietnamese women. Vietnamese women have the highest rate of cervical cancer incidence when compared to all other racial or ethnic groups in the United States.

Among Vietnamese women living in California, cervical cancer is the second most common cancer and Vietnamese women are five times as likely to develop cervical cancer when compared with white women in the United States.

"We didn't know about cervical cancer, because in our country they don't teach us about it," said a Vietnamese woman, who supervised the community lay workers for the UCSF study. "But that is

beginning to change."

Chris Jenkins, executive director of the Vietnamese Community Health Promotion Project, and co-investigator for the study, said many of the women in the study had never been screened. "The community we studied are first generation immigrants who are coming from a poor country without many health resources," he said. "The focus of medicine in Vietnam is acute care. Doctors are not trained in preventative medicine."

To get Vietnamese-American women in the San Francisco area to recognize the importance of receiving and maintaining annual pap smears and breast examinations, the *Opening Pathways* study used community outreach interventions. "We got the idea from a project in San Diego that was using "Promotores" to educate Hispanic women about screening," Jenkins said. (See also, *Closing the Gap*, March 2000, p. 9, *Border Vision Fronteriza*.)

Community lay workers were recruited and trained, with 10 serving as neighborhood leaders and 30 trained as assistants. The interventions were held in Vietnamese, in the women's homes. Participants were formally educated on risk factors, screening recommendations, benefits of screening, and descriptions of procedures.

Over a three-year period, approximately 40 indigenous community health workers conducted 86 small-group sessions on cervical cancer with women in a low-income district. There were also sessions on general prevention and breast cancer.

Focus groups helped determine the best ways to reach the women. The materials—wall posters, brochures, booklets, and promotional items like magnets and pot holders—were all created in Vietnamese and incorporated Vietnamese values. The brochure, which is soon to be published nationally by the National Cancer Institute, urged women to seek routine preventive care and screening.

"The small-group format definitely contributed to the success of the interventions," Jenkins said. "These were small meetings with friends, mothers, aunts. The women knew each other and that is the power in this approach. There was a real sense of support among the women."

For more information on the study, call Chris Jenkins, Vietnamese Community Health Promotion Project, (415) 476-0557. Or contact Eva Moya, senior project coordinator, Border Vision Fronteriza (BVF), (915) 585-7612. BVF uses similar outreach strategies for Hispanic women in San Diego. ❖

Barriers to Screening

Although successful, the *Opening Pathways* study was not without barriers. "Vietnamese women tend to be shy and modest, and don't like to be examined below the waist," Jenkins said. "There is a certain shame that accompanies getting screened because it is associated with sexual activity," Jenkins added. Other common barriers to screening:

- **Young women may face shame.** In Vietnam, young women should be virgins; getting a Pap smear may imply that she is sexually active when she shouldn't be.
- **Older women think it doesn't apply to them.** Some of the older women who are post-menopausal and not sexually active think they don't need to be screened. But they are at greater risk for cervical cancer because of their age.
- **Living in a small, intimate community.** Be-

cause of community structure, patients may know doctors. This may make it difficult to disrobe in front of a male community doctor whom the women may encounter in public. Health providers should make sure a female doctor is available.

- **Doctors may not think it is necessary.** Some Vietnamese doctors may still think pap smears aren't necessary due to training they received in their home countries.
- **Other medical conditions are likely to come up.** Because the community in the study was poor, the women often had other medical questions. When educators are trying to address cancer screening, things like aching backs, stomach aches, or a sick mother, sometimes come up. Providers should be prepared to address these. ❖

Intercultural Cancer Council Advocates for Minorities and Underserved

By Jennifer Brooks

Susan Shinagawa detected a lump in her breast nine years ago when she was 34 years old. Her doctor told her it was nothing to worry about. She was too young to have breast cancer, with no familial history of the disease. “Besides, ‘Asian women don’t get breast cancer,’” Shinagawa said her doctor told her. He was wrong.

“It is dangerous when experts tell Asian women they don’t get breast cancer,” said Shinagawa. “You don’t hear physicians telling white women they don’t get breast cancer.”

Now a cancer survivor, thanks to seeking a second opinion and insisting on a biopsy of the lump, Shinagawa tries to make sure her experience doesn’t happen to others. She serves as chair of the Intercultural Cancer Council (ICC), the nation’s largest cancer coalition addressing disparities in incidence, mortality, and survival rates among racial and ethnic minority and medically underserved populations.

The ICC promotes policies, programs,

partnerships, and research that helps eliminate cancer-related health disparities in the United States and its associated territories.

While the risk of breast cancer continues to rise with age, premenopausal breast cancer is more prevalent in minority women, said Shinagawa. “For African American and Native Hawaiian women who experience a disproportionately high rate of premenopausal breast cancer, it poses a serious threat because it is a more virulent form of the disease,” she said. “Little is known about what is happening in Indian country. Women from many Asian and South American countries seem to lose a protective factor against breast cancer when they immigrate to the U.S. More research needs to be targeted on these special populations.”

We cannot forget the medically underserved, according to Armin Weinberg, PhD, of Baylor College of Medicine in Houston, co-founder and past chair of ICC. “You

really cannot separate race and poverty because they have so much in common. That is what has brought the ICC together,” he said.

The ICC has been critical in the past of what they called the National Cancer Institute’s (NCI) lack of commitment to understanding the nature of cancer among racial and ethnic minorities and the underserved. In his testimony before Congress—which helped prompt the implementation of the Institute of Medicine (IOM) study, *The Unequal Burden of Cancer*—Dr. Weinberg stated a need for more cancer research on minorities and underserved populations, and called on NCI to significantly retool its culture and priorities.

Dr. Weinberg now believes NCI is headed in the right direction with its development of a comprehensive strategic plan to eliminate disparities in cancer rates. He also thinks Harold P. Freeman, MD—who was recently named NCI’s associate director for reducing health disparities—is the best person to get the job done, citing Dr. Freeman’s research on race, poverty, and cancer.

“Dr. Freeman can clearly help bridge scientific issues with community-based concerns,” said Dr. Weinberg. “He understands the community, he works in it, he lives in it.”

The ICC not only impacts what happens at the national level, but also looks at “helping local communities as well as learning from them through the ICC National Network,” said Shinagawa. One of ICC’s priorities is information dissemination. As such, the ICC sponsors a Biennial Symposium series so that people from all walks of life—cancer survivors, physicians and scientists, students, as well as national and community leaders—can share information on cancer.

The ICC has been successful in its networking activities that promote information dissemination. “As our friend Dr. Freeman has often said, ‘We must be supportive of discovery but insistent on delivery,’” Dr. Weinberg said. “If we can’t apply it, why do it?”

For information on the ICC and its Biennial Symposium on Minorities, the Medically Underserved & Cancer, visit its Web site: <http://iccnetwork.org>; or call: (713) 798-5383. ❖

Knowing Where to Aim

By Jennifer Brooks

Harold P. Freeman, MD, began his new job with NCI as associate director for reducing health disparities in early August 2000. He spoke with *Closing the Gap* on how he will approach his new duties.

“We have to get a better handle on the real variables that are causing disparities, and we should observe the data and research that have taken place so far that point to things like racial difference,” Dr. Freeman said.

“We need to look through the lens of racial and ethnic categories and try to understand the deeper causes of health disparities such as poverty, social injustice, and cultural differences.”

For example, people who live in poverty do not do as well as others when they develop cancer because they have no easy way to get into the system, according to Dr. Freeman. “Poverty itself is an extraordinary driving force in causing disparities,” he said. “Poverty means more than income or wealth. Poor people tend

to be less educated, so education in itself is a critical factor.”

“Lifestyle, attitude, and behavior can be influenced by education,” said Dr. Freeman. For instance, 85 percent of lung cancer—the number one cause of cancer death in America—is related to cigarette smoking, according to Dr. Freeman. He said people who are less educated and who are poorer tend to smoke more.

“Poverty also causes poor living conditions, lack of information, lack of access to health care and preventive health care,” said Dr. Freeman. “This is the framework from which I will be looking at these things. I need to better understand, even though I’ve spent my entire career—32 years—looking at these issues,” he said. “Then, with evidence coming out of NCI and various other kinds of studies, we need to promote policies both at the federal and local level that will allow us to have an impact on correcting those problems.”

Studies Explore Patient, Physician Perspectives on Treating Pain Effectively

By Houkje Ross

Patients have the right to control pain associated with cancer and need to learn how to talk with their doctors about it, according to the Pain Research Group (PRG) at the University of Texas M.D. Anderson Cancer Center. Educating minority patients about their pain and how to manage it could help reduce the severity of pain many minority cancer patients face.

The PRG is conducting clinical studies called Pain Relief Education for Minority Outpatients (PREMO). These trials, which are targeting nearly 900 Hispanic and African American patients, are using easy-to-understand print and video materials to educate African Americans and Hispanics who have cancers of the breast and prostate, solid tumors, or hematological malignancies—lymphoma or leukemia. PREMO patients learn how to describe pain and talk with their doctors about it.

Patricia Washington, DSN, RN, coordinator for the PREMO trials, said persistent pain associated with cancer becomes more pronounced when the cancer has metastasized, or spread to other parts of the body.

“This is when cancer becomes very painful,” Washington said. Cancer pain is continuous, and without medication, the pain usually gets worse rather than better. Research suggests that many cancer patients, minority and white, are reluctant to report their pain and that is when under medication may result.

Patients Often Face Fear

Washington said that patients sometimes feel “overwhelmed” by what a doctor is telling them and are afraid to ask questions or admit they are in pain.

“A patient may not understand the technical language a doctor is using and nod his or her head yes, when he or she really doesn’t know what the doctor is saying in the first place,” she said.

The Seattle, WA based International Association for the Study of Pain (IASP) said that the fear of becoming addicted to pain medication could play a large part in the reluctance to use medication. IASP, which is an international, multidisciplinary, non-profit professional association dedicated to furthering research on pain and improving the care of patients with pain, also said that many minority patients who are older, less educated, or lower income, are more likely to have these fears.

“Many patients don’t like to take their pain medication because they fear being out of control,” Washington said. It is common for

patients to have to take a pill every four hours to manage cancer pain, but many patients and family members don’t understand this and think it is too much, she added.

The PREMO studies will assess whether patient education on pain management will improve pain control, according to the Pain Research Group. The studies are intended to help reduce the impact of pain on daily life, and improve the quality of life of patients.

Physicians Have Fears Too

Patients are not the only ones reluctant to use prescription analgesics to decrease cancer pain. Physicians and doctors often have a hard time with it as well. Analgesics, which are medications such as codeine for moderate pain and morphine, Demerol, or dilaudid for heavier pain, are the types of drugs most often prescribed to cancer patients.

Recent studies by PRG show that minorities with cancer often suffer more from pain due to under-medication. Researchers found that nearly 62 percent of patients at institutions serving predominantly African American patients were not prescribed adequate analgesics. At institutions serving primarily Hispanics, 82 percent met the criteria for under-medication.

According to a University of Wisconsin Medical School survey, physicians tend to overestimate the side effects from medications used to treat cancer pain.

“Doctors may not take the time to assess pain accurately in their patients or they may not know the correct standards to follow in prescribing pain medications,” Washington said. “Sometimes they are even afraid of losing their license for prescribing too much pain medication,” she added.

A recent PRG surveys asked 1,177 oncology physicians to rank 12 barriers to adequate cancer pain management. Lack of proper assessment and a need for better communication about pain between patient and health care providers were ranked as the greatest barriers.

Washington said that time is often a barrier, too. “Community hospitals see large numbers of patients, so time is limited for doctors. They are just so busy,” she said.

According to IASP, proper assessment of pain comes when health care workers take into account a patient’s mood, attitude, coping efforts, and resources, the responses of family members, and the impact of pain on their lives. A patient’s experience could be difficult to communicate because the patient and provider may have different

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“Fears of becoming addicted to pain medication may also play a large part in the reluctance to use medication.”

Fatalism Interferes with Cancer Treatment

By Houkje Ross

Fatalism is a problem for many low income and uninsured patients who face cancer. These populations often have larger problems, like dealing with day-to-day survival issues. Cancer treatments are not a top priority.

Patricia Washington, DSN, RN, a nurse at University of Texas M.D. Anderson, explains cancer fatalism as “an individual’s belief that death is inevitable when cancer is present.”

According to Washington, who has worked in oncology since the mid- 1980’s, cancer fatalism is believed to be the result of a complex psychological cycle that is charac-

terized by perceptions of hopelessness, worthlessness, meaninglessness, powerlessness, and social despair. Typically, these individuals are poor, elderly, and black, she said. They usually have low levels of education and a minimal understanding of cancer, which can perpetuate fatalism.

“Many in minority communities have a sense of ‘deserving to die’ because they think they lived their lives in the wrong way or that the cancer is a punishment from God,” Washington said. “This view often has a paralyzing effect, imposing a sense of powerlessness over the cancer patient’s family, friends, and neighbors. In many instances, cancer becomes

a silent epidemic, a taboo subject, unmentionable even among close family friends,” she added.

For socio-economically disadvantaged individuals, cancer is just another added burden that they have to face besides the problems of money, or feeding their children, Washington said.

Finding out that you have been diagnosed with cancer is hard for some patients, according to Washington. Facing the fact that you have cancer is very difficult for some individuals and many don’t come back after they find out, she said.

Washington, who provides cancer education to minority populations, talked about a recent 27-year-old African American male patient with lymphoma—a disease which she said was almost one hundred percent curable. Washington said the man would not follow up with treatments, since he feels he is going to die anyway. “Once every two months he will show up for treatment,” she said.

Earlier in life, Washington said she watched her aunt die from breast cancer. She was in nursing school at the time and moved in with her aunt to care for her.

“After having a mastectomy, it was recommended that she have postoperative chemotherapy, but she refused,” Washington said. “The cancer continued to spread, she was in terrible pain, and she was only taking about half of her prescribed pain medication. She was in her early fifties when she died,” Washington added.

In addition to working as a full-time nurse, Washington works to educate minorities on prevention and detection of cancer. She especially tries to instill prevention early.

Screening is key to early detection. A mammogram can detect a cancerous growth the size of a pin head in the breast. “If you can feel a lump, it has probably been in your body for almost two years,” Washington added. ❖

Managing Pain...from page 6

languages, experiences, expectations, and frames of reference. Other factors that sometimes contribute to pain intensity are the psychological influences. Fear, anxiety, depression, or social isolation can magnify cancer pain, according to IASP.

Culture and Language are Important

In a 1998 study conducted by the City of Hope National Medical Center in Duarte, CA, researchers stressed consideration for a patient’s overall beliefs and values. Some Hispanic patients may use folk healthcare practices, the study said. Researchers also recommend that physicians incorporate the patient’s practices and beliefs into the plan of care when possible and involve family members and friends. Identifying one key family contact can also help.

Researchers also emphasized the use of bilingual instructions for medications. En-

sure that instructions for medications are available in Spanish and understood by the patient and the caregiver, the report said. The study went on to say that the lack of understanding instructions for taking pain medication was the most common reason cited for noncompliance with pharmacological treatment.

To help physicians assess pain in clinical and research settings, PRG developed a survey called the *Brief Pain Inventory*. The *Brief Pain Inventory* is designed to aid physicians in assessing the severity of pain, its impact on daily functions, location, and types of pain medications that a patient may already be taking. The *Brief Pain Inventory* is available in sev-

eral languages including Chinese, Japanese, Spanish, and Vietnamese.

For more information on *PREMO Studies*, or the *Brief Pain Inventory*, contact the *Pain Research Group at the University of Texas M.D. Anderson Cancer Center*, (713) 745-3470. ❖

Sometimes physicians are even afraid of losing their license for prescribing too much pain medication.

Turning Cancer Into a Positive Force in Your Life

By Bobbi de Córdova-Hanks, director, Bosom Buddies of the Women's Center of Jacksonville, FL

When I first used the words “cancer survivor” 14 years ago, I never realized they would become two of the most important words in my life. I remember the experience vividly.

I was at the airport to meet my mother and sister, who were coming to be with me for my mastectomy surgery. I had undergone a lumpectomy several years before to remove a very large tumor, leaving me with 85 staples across my chest. Suddenly as I went through security, the alarm sounded. As I patted my pockets looking for my keys, I realized the staples had set off the alarm.

I pulled a female security officer to the side and said, “I’m a cancer survivor and I have staples across my chest. Tomorrow I’m having my breast removed and I’m here to meet my family.” She gently patted me down, walked me alongside the entrance and wished me Godspeed.

As I walked down the long corridor I thought how easily I said “cancer survivor.” I never said “victim.” For the first time since my diagnosis of late stage 3 breast cancer several days before, I saw the light at the end of the tunnel. I made a conscious choice at that moment to focus on life and not the disease. When my mother, sister and I walked past security, I gave them the thumbs up sign and they all stood there applauding saying they would keep me in their prayers. How could I lose the battle with even total strangers praying for me?

As the doctor prepared me for the worst, I looked over my shoulder to see who he was talking to. It couldn't be me. I was healthy as a horse and had no history of breast cancer in my family. Little did I know that one of the biggest risk factors is just being a woman. As I listened to all the terrible statistics, I thought, this doesn't have to be me. Statistics are written about dead people, but as long as I'm alive and kicking, I can prove the statistics wrong.

That's when my life changed dramatically. I began to think how wonderful it would be to have someone to talk to who had been through this before. Since there were no support groups in my area, I set about educating myself as best I could about this disease and made a silent pact with God. I promised God if I survived I would reach out to help other women through their breast cancer journey. And that's when the seeds of Bosom Buddies were planted.

As Bosom Buddies grew and I became more focused on survivorship, I learned that we are a nation of 8.4 million survivors, most of us living five years after our diagnosis. I also learned we need to advocate for equal job opportunities after a diagnosis, and should have the right to health insurance coverage, regardless of preexisting conditions. More than anything, I learned to be proud to be a cancer survivor.

When I was diagnosed with metastasized thyroid cancer in 1999, I suddenly found myself revisiting old myths and fears. The words “you have cancer,” are words I never expected to hear again.

I thought about my life and my work with cancer survivorship over the last decade. At that moment I decided that cancer had been a positive force in my life. It made me stop and smell the roses. It gave me the opportunity to tell my family and friends how much I loved them, and more than anything, it gave me the chance to make a difference in the world. I knew from that moment on I would always continue to seek knowledge, never lose hope, and always take action. How lucky I am to be a cancer survivor!

For more information on Bosom Buddies at the Women's Center of Jacksonville, FL, call (904) 356-3300. To book a speaker, contact: Hanks-Livingston, Inc. (904) 739-1510. ❖

It gave me the opportunity to tell my family and friends how much I loved them, and more than anything, it gave me the chance to make a difference in the world.

10 Sources of Help in Paying for Cancer Services

By Houkje Ross

Bobbi de Córdova-Hanks was working as an editor for a music publication when she was diagnosed with cancer. “Soon after my company found out I had cancer, I was fired. For two years I didn’t have a job or health insurance,” she said. She ended up with a \$14,000 medical debt. “I didn’t know that pharmaceutical companies could have helped me pay for my medications,” she said. Here are some places to look for extra help:

- 1. Pharmaceutical companies.** Almost all pharmaceutical companies have an Indigent Drug Program that provides medications to people who cannot afford them. A patient or a physician can call the pharmaceutical company for an application. Amounts and eligibility vary from program to program. For a list of companies who participate in these programs, contact: Cancer Care Inc. toll-free at 1-800-813-HOPE, or visit its Web site: <http://www.cancercareinc.org>. NeedyMeds also provides information on pharmaceutical company programs. Visit its Web site at: <http://www.needymeds.com>.
- 2. Hill Burton Program.** This is a program through which hospitals receive construction funds from the federal government. Hospitals that receive Hill-Burton funds are required to provide services to people who cannot afford to pay for hospitalization. A brochure about the program is available by calling 1-800-638-0742; or visit <http://www.hrsa.dhhs.gov/osp/dfcr>. The brochure is also available in Spanish.
- 3. Community Voluntary Agencies.** Service organizations like the Salvation Army, Lutheran Social Services, Jewish Social Services, Catholic Charities, and the Lions Club may offer help. Some churches also provide financial help or services to their members. Look in your phone directory.
- 4. Cancer Fund of America.** This organization is dedicated to providing direct aid to financially-indigent patients in the form of goods, including canned foods. Call CFA at 1-800-578-5284 or visit its Web site at: <http://www.cfoa.org>.
- 5. Helping Hands Resource Database.** Cancer Care Inc.’s database maintains organizations by state, name, or type of services provided. Information is available on the following types of services: transportation, housing, finances, elderly, children, homecare/hospice, counseling, rehabilitation, and survivor concerns. Call Cancer Care Inc. at 1-800-813-HOPE, or visit its Web site: <http://www.cancercareinc.org>.
- 6. United Way Agencies.** Many local United Way agencies operate an information and referral service (often called First Call for Help, or Helpline) that lists a variety of local services. Check your phone directory for a United Way office in your area.
- 7. Medicare.** The program provides colorectal and prostate cancer screenings, as well as annual mammograms. All women, regardless of age, are eligible for pap smears once every three years. For most of these services, patients pay 20 percent of the total amount. On June 7, 2000, the White House announced an executive order that mandates Medicare to pay for patient care and treatment costs for patients enrolled in clinical trials. For more information, call 1-800-772-1213; or browse its Web site: <http://www.medicare.gov>.
- 8. Medicaid.** This medical assistance program provides health insurance for low income and the poor elderly, blind, or disabled, as well as certain groups of children. Each state program is different. Contact your local department of social services or the Social Security Administration.
- 9. Airlifeline.** Airlifeline provides free flights to patients who cannot afford the cost of commercial airfare when traveling to their medical facility. There is no charge for patients or medical facilities. For more information, call toll-free 1-877-AIR-LIFE; visit its Web site at <http://www.airlifeline.org>.
- 10. American Cancer Society.** The Guestroom Program is a cooperative effort between ACS and Westin Hotels that provides free overnight accommodations for needy cancer patients who must travel to receive treatment. ACS also has 16 Hope Lodges in 13 states. Hope Lodges are temporary residential facilities that provide sleeping rooms and related facilities free of charge for any cancer patient undergoing outpatient treatment and their family members. For more information on these programs, call your local ACS chapter. ❖

Men Need to Know Their Options

By Jean Oxendine

African American men have the highest incidence and mortality rates of prostate cancer in the world. If treated, however, survival rates are equal to those in other populations. Knowing current screening and treatment procedures is critical for these at-risk men.

“Studies show that, stage-for-stage, equal treatment to equal treatment, race does not make a difference in treating prostate cancer,” said Otis Brawley, MD, director of the National Cancer Institute (NCI), Office of Special Populations Research. Except for skin cancer, prostate cancer is the most common type of cancer in American men. Nearly 179,300 men in the U.S. were diagnosed in 1999, according to NCI. Being older and eating a diet high in fat can increase a man’s chances of getting the disease. Genetic factors may play a part for men under 60 years of age who are diagnosed with prostate cancer. Studies also show a dramatic difference in incidence of prostate cancer among men from different countries.

Screening Controversy

According to Dr. Brawley, the U.S. Preventive Services Task Force announced that the official HHS stand recommends against routine prostate cancer screening for all men because it has not been proven to save lives. “Although no medical organization strongly endorses screening for all men, men should be aware of the risks and benefits of screening,” Dr. Brawley said.

Both the American Cancer Society (ACS) and the American Urological Association (AUA) have policy guidelines on screening. According to the ACS, both prostate specific antigen (PSA) and digital rectal examination should be offered annually, beginning at age 50 years, to men who have at least a 10-year life expectancy, and to younger men who are at high risk. Information should be provided to patients regarding potential risks and benefits of intervention. ACS further recommends that men in high risk groups, such as those with strong familial predisposition or

African American men, may begin at a younger age (e.g. 45 years). The AUA endorses ACS’s policy on screening.

The *Journal of the American Medical Association* (May 1999) reports, “while screening for PSA has led to increased detection of the disease, it is unclear whether screening is associated with the decline in mortality that has been seen in the last few years.”

Proponents say annual screening is important because most cancers detected through screening are in an intermediate grade and the PSA test allows the detection of potentially dangerous cancers that have a high likelihood of affecting a patient’s life. Opponents argue PSA tests can produce a number of false-negative and false-positive results, leading to treatment that may reduce a man’s quality of life.

Patients should do research

“Once a patient is diagnosed, it is very important for him to talk with a doctor about possible treatments because some may prolong life,” Brawley said. Brawley counsels patients on their options, and tells them they must read, think hard, and talk to experts about each of the types of treatments. “If a doctor says, ‘my way is better than the other ways,’ walk out of the office,” said Brawley. He said getting treatment from a reputable provider and making sure they do a good job are critical.

Screening Options

Tests commonly used to detect prostate cancer include:

Digital Rectal Examination. A doctor feels the prostate gland through the rectal wall to check for bumps or abnormal areas.

Transrectal Ultrasonography. A probe that is inserted into the rectum sends out high-frequency sound waves. The waves bounce off the prostate gland and produce echoes that a computer uses to create a sonogram.

Symptoms of prostate cancer can include:

- Frequent urination, especially at night;
- Inability to urinate;
- Trouble starting or holding back urination;
- A weak or interrupted flow of urine;
- Painful or burning urination;
- Blood in the urine or semen;
- Painful ejaculation;
- Frequent pain or stiffness in the lower back, hips, or upper thighs.

These can be symptoms of cancer, but more often they are symptoms of non-cancerous enlargement of the prostate. It’s important to check with a doctor.

Prostate Specific Antigen. A blood sample is drawn to determine the amount of PSA present. PSA is a marker that, if present in higher than average amounts, may indicate prostate cancer cells. But PSA levels may be higher in men who have non-cancerous prostate conditions. The only true confirmation of prostate cancer is by a microscopic examination to identify cancerous prostate tissue.

Types of Treatment

Treatments commonly used for prostate cancer are:

- surgery;
- radiation therapy;
- hormone therapy;
- chemotherapy; and
- biological therapy, which uses the body’s immune system to fight cancer.

The type of treatment a patient chooses will depend on the stage of the disease, and the patient’s age and overall health.

For more information, call NCI’s Cancer Information Service at 1-800-4-CANCER (1-800-422-6237); TTY at 1-800-332-8615. Web site: <http://cancernet.nci.nih.gov/> ❖

More Research Needed on Breast Cancer In Black Women

By Michelle Meadows

African American women are more likely to die of breast cancer than any other racial and ethnic group. While White women are more likely to develop breast cancer, Black women have the highest death rate from the disease.

Being diagnosed at later stages is one factor, says Edwin T. Johnson, MD, author of the recently published second edition of the *Breast Cancer/Black Woman*, and director of the Montgomery Urgent Care and Diagnostic Center in Montgomery, AL. "We've got to look for it earlier in black women," Dr. Johnson says. He starts annual screening mammograms for black women at age 30 in his practice. "Breast cancer in black women under 40 is twice as frequent as the rate for whites. In most instances, by age 40, the cancer has spread in black women."

The American Cancer Society recommends mammograms every year starting at age 40 for all women. The National Cancer Institute's (NCI) stance is that women in their 40s should have mammograms on a regular basis—every one to two years. NCI also recommends that women at higher risk seek medical advice for screening recommendations.

Whether Black women should have different mammogram screening guidelines than the general population needs further investigation, said Lovell Jones, PhD, co-founder of the Intercultural Cancer Council, and professor and director of experimental gynecology and endocrinology at the University of Texas MD Anderson Cancer Center.

Dr. Jones is planning a summit for September 2000 that will bring together leading cancer researchers to explore such unanswered questions about breast cancer and black women. Topics will range from genetics to racism. The closed meeting will also include breast cancer survivors. Among the issues to be considered:

What are the differences in treatment?

Lack of access to care, especially lack of health

insurance, is among the biggest problems for black women, according to Lucile Adams-Campbell, PhD, director of Howard University's Cancer Center and a professor of medicine. "Studies show that access to treatment might be very different for black women," she says, noting that mammogram screening rates are approaching the rates of white women.

Why are there differences in incidence?

"Access certainly plays a role in mortality, but

Breast Cancer Rates by Race and Ethnicity

Incidence (Rate of new cases)

Whites: 113.2 per 100,000 women
Blacks: 99.3 per 100,000
Asian/Pacific Islander: 72.6 per 100,000
Hispanic: 69.4 per 100,000
American Indian: 33.9 per 100,000

Mortality (Death rate)

Blacks: 31.4 per 100,000
Whites: 25.7 per 100,000
Hispanics: 15.3 per 100,000
American Indians: 12.3 per 100,000
Asian/Pacific Islander: 11.4 per 100,000

Source: *Cancer Facts & Figures 2000*, American Cancer Society.

there may be other factors involved with incidence," Dr. Jones said. "Why is breast cancer 50 percent higher in Black women under 35?" Breast cancer occurs about five to 10 years earlier in Black women than White women, and the incidence of breast cancer is also higher in premenopausal black women, he added. "This says something is going on that is not influenced by access."

Is breast cancer more aggressive in Black women? When breast cancer is discovered in black and white women at the same stage, is it more aggressive? Dr. Jones says "there are studies that have pointed to breast cancer

being more aggressive in black women, but there are not a volume of such studies." Experts say breast cancer in African American women may be more likely to be estrogen-receptor negative. Estrogen receptor negative tumors tend to be more aggressive, Dr. Jones explains. That means drugs that block estrogen aren't as effective and the tumors are more difficult to treat.

The September meeting will address many questions and result in a report of findings and recommendations. The meeting is receiving financial support from NCI, the National Institute of Environmental Health Sciences, Columbia University's African American Breast Cancer Project, Ortho-Biotech, and Amgen. Sponsors include the University of Texas M.D. Anderson Center, and Howard University Health Sciences Center. ❖

Tamoxifen Found Equally Effective for Black and White Women in Reducing a Type of Breast Cancer

The NCI announced in May 2000 that new analysis shows tamoxifen is as effective for Black women as it is for White women in reducing the occurrence of "contralateral" breast cancer—cancer that develops in the healthy breast after cancer in the opposite breast has been treated. In addition, the drug does not cause more side effects in Black women as some had originally feared. Black women at increased risk for breast cancer can also benefit from tamoxifen as a preventive drug. According to NCI, this finding may help boost recruitment of Black women into the Study of Tamoxifen and Raloxifene (STAR), a breast cancer prevention study comparing those two drugs in women with high risk of the disease.

To contact a STAR near you, call NCI's Cancer Information Service at 1-800-4-CANCER. ❖

American Cancer Society Targets Research Dollars for Poor, Underserved Populations

Recognizing that disparities exist in the burden of cancer, the American Cancer Society (ACS), the nation's leading voluntary health organization, has targeted poor and underserved as populations in need of increased research funding.

Specifically, the Society's nationwide research program has requested proposals from researchers investigating specific issues related to these populations with the hope of eventually finding solutions to help these various groups gain access to and achieve the highest level of health care possible.

"Funding research in the areas related to the needs of the poor and underserved is vitally important to the Society's mission," said John Stevens, MD, vice president for extramural grants and the lead staff researcher for the ACS. "So in addition to the regular research proposals affecting these populations, the ACS has issued a special call to investigators for research applications in this area."

While one in three Americans will have personally experienced cancer during their lifetime, the nation's poor and underserved people are more statistically at risk of cancer than they need to be, said Dr. Stevens. "People who are poor often lack health insurance and access to high-quality care, often lack education or may not know English well enough to ask questions or read prevention information. In addition, certain populations may even be isolated geographically and culturally from majority health care opportunities. As a result, these groups often develop certain cancers more frequently and die at higher rates than other Americans.

The ACS's request for targeted grant applications for studies addressing cancer issues among the poor and underserved has already resulted in nine awards totaling nearly \$5 million. Some of the grants include:

- **"Gatherings of Wellness" for Native American Women.** Early detection becomes the most important tool for reducing cancer deaths in the American Indian population, which has the low incidence rates of most

cancers, yet the poorest survival rates from cancer of any other ethnic group in the U.S., said Linda K. Larkey, PhD, of the Arizona Cancer Center at the University of Arizona. American Indian women in the Phoenix area will participate in six-month interventions intended to improve screening rates for breast, colon, and cervical cancer. In the first project, Community Health Advisors—women selected and trained from the target community—will educate friends and neighbors about the importance of cancer screening. The peer advisors will participate in the second project, "but in a novel way that is expected to maximize effectiveness and enhance the maintenance of changed behavior," Dr. Larkey said. In the second intervention, peer advisors will bring women together to participate in health forums called "Gatherings of Wellness" that will focus on the same set of prevention and screening topics used in the first project, but in a culturally sensitive way.

- **Neighborhood Factors.** Convincing people to change their behaviors, whether it is to quit smoking, eat a more healthy diet or visit the doctor more frequently, is a difficult task. Therefore, research into understanding how people adopt change is vital. One research project supported by the American Cancer Society is examining the individual's relationship to the community. Factors being evaluated include trust among neighbors in a community, a sense of belonging, involvement in community activities, and trust in organizations to act on behalf of the community. Elizabeth Baker, PhD, at St. Louis University, said the results from her study should help advance the next step of delivering interventions based on an understanding of the social, community, and neighborhood factors that can influence a person's behavior.

For information about cancer, call toll-free at 1-800-ACS-2345 or visit the American Cancer Society Web site at www.cancer.org. ❖

Special Populations Network Launched to Address Burden of Cancer

Bethesda, Md. (NCI)—Richard D. Klausner, MD, director of the National Cancer Institute (NCI), recently announced a \$60 million program to address the unequal burden of cancer within special populations in the United States. The Special Populations Networks for Cancer Awareness Research and Training are intended to build relationships between large research institutions and community-based programs.

Eighteen grants at 17 institutions will create or implement cancer control, prevention, research, and training programs over the next five years in minority and underserved populations. The cooperative relationships established by the networks will be used to foster cancer awareness activities, support minority enrollment in clinical trials, and encourage and promote the development of minority junior biomedical researchers.

"This initiative is one of the largest of its kind in the federal government. It is designed to encourage people from the community to work with scientists to find ways to address important questions about the burden of cancer in minority communities," Klausner said. He also noted that cancer is one of the six focus areas in the Department of Health and Human Services' Initiative to Eliminate Racial and Ethnic Disparities in Health.

The Special Populations Networks incorporate knowledge gained from the recently concluded Leadership Initiatives on Cancer within Appalachian, Black, and Hispanic populations. Projects focused on cancer awareness, reducing cancer incidence and mortality, increasing cancer survival, and improving access to health care within minority and medically underserved populations. ❖

The Office of Minority Health has a new and improved Web Site! Visit us at: <http://www.omhrc.gov>.

APPEAL Tackles Tobacco Through Leadership Program and Policy

By Rod Lew, MPH, Association of Asian Pacific Community Health Organizations

The topic of tobacco has saturated the public news for the past two years—from the tobacco industry settlement with the state attorneys general, to “The Insider” movie, to the record setting class action lawsuit award against the tobacco companies in Florida. In addition, President Clinton has identified cardiovascular disease, which is impacted by tobacco, as one of the top six health disparity areas for racial and ethnic minorities.

Reduction of tobacco use remains a challenge, especially for those communities facing health disparities. For the diverse Asian American and Pacific Islander (AAPI) community, tobacco is a major issue that will require strong community leaders, comprehensive health programs, and the support of health and policy makers.

The Asian Pacific Partners for Empowerment and Leadership (APPEAL) is one group that is doing something about the tobacco issue. APPEAL, which is a project of the Association of Asian Pacific Community Health Organizations (AAPCHO), is a national AAPI tobacco control network of more than 200 organizations. APPEAL has been forging a national movement in the AAPI community for the past six years. This includes developing a comprehensive program to address the Healthy People 2010 goal of reducing smoking prevalence to 12 percent for all populations.

Tobacco control presents a major challenge because males in some AAPI ethnic groups like Laotians, Cambodians, and Native Hawaiians have smoking prevalence rates ranging from the 35 percent to 70 percent—well above the national goal.

Furthermore, the tobacco industry has increased marketing to the AAPI population, which has had a dramatic impact, especially on traditionally non-smoking females. And

cigarettes aren't the only form of tobacco use. Some communities, such as Pacific Islanders, chew betel nut mixed with tobacco.

With funding from the Robert Wood Johnson Foundation, APPEAL has focused recent efforts on building AAPI community capacity through its leadership development programs. After a successful first year, AP-

Reduction of tobacco use remains a challenge, especially for those communities facing health disparities.

PEAL has launched the second cycle of the APPEAL Leadership Program 2000-2001.

The APPEAL Leadership Program is a year-long fellowship that attempts to build individual skills and competencies in addressing tobacco in one's community. The program aims to develop community capacity to implement local tobacco control activities.

For this year's leadership program, fellows will participate in the six-day APPEAL Leadership Summit, to be held at the Ramada Plaza Hotel in San Francisco from October 8-13, 2000. The conference portion of the summit, which is open to the public, will be held on October 10-11 of that week.

APPEAL has also been addressing policy

issues related to tobacco. On July 23-24, 2000, APPEAL assisted the American Legacy Foundation in convening a special population forum to help AAPIs develop a plan to address tobacco issues. Then on July 25, APPEAL, the Robert Wood Johnson Foundation, and the American Legacy Foundation convened the historic National Symposium on Tobacco Control in Asian American and Pacific Islander Communities in Bethesda, Maryland.

Eight national tobacco control organizations and offices and four state health departments were represented at this meeting to address comprehensive tobacco issues for AAPIs. Among these groups were the U.S. Department of Health and Human Service's (HHS) Centers for Disease Control and Prevention's Office on Smoking and Health, National Cancer Institute, and Center for Substance Abuse Prevention; the Campaign for Tobacco-Free Kids; American Cancer Society; and the American Lung Association.

APPEAL drafted policy recommendations to highlight these critical issues and identify commitments from these organizations to address AAPI tobacco control. The final draft of the APPEAL policy manual on tobacco will be forthcoming later this year.

Mr. Lew is director of APPEAL. He can be reached at 510-272-9536; or e-mail him at: rodlew@aapcho.org.

Medicare to Pay Patient Care Costs in Clinical Studies

Washington, DC (NCI)—President Clinton recently issued an executive memorandum directing the Medicare program to reimburse providers for the cost of routine patient care in clinical trials. The memorandum also provides for additional actions to promote the participation of Medicare beneficiaries in clinical studies.

Patients and physicians interested in trials can find them via a new database that lists clinical trials around the country. Its Web address: <http://clinicaltrials.gov/ct/gui/c/b>. Information specifically on cancer studies can also be obtained by calling NCI's toll-free number, 1-800-4-CANCER; or by browsing: <http://cancertrials.nci.nih.gov>.

CBOs Play Critical Role in Helping Patients Get Treatment

By Houkje Ross

Too often minorities, ethnic groups, and others who are medically underserved do not get the treatment they need. Community-based organizations can provide education and outreach to point people to low-cost screening facilities.

“One of the most difficult things in the world is getting referrals for patients who have been diagnosed with cancer,” said Bobbi de Córdova-Hanks, director of Bosom Buddies of the Women’s Center of Jacksonville, FL. That is because many minority patients may be able to obtain access to low-cost or free cancer screening, but still face the dilemma of not being able to pay for treatment.

Establishing yourself as a credible organization in the community can help, said de Córdova-Hanks. “When I call a doctor and ask for help, he knows who I am and is more likely to help me find treatment for patients.”

Doctors who work in community centers in Denver, CO, also establish themselves within the local hospital by providing attend-

ing services one day a month and teaching in the residency program, said Terence Shea, RN, director of community health nursing at Denver Health. Shea said this enables them to know the ins and outs of the hospital system, and makes it easier to get treatment for patients.

Denver Health is a public health care system that coordinates services at community-based health centers and clinics with hospital care. It is a model program for communities interested in bridging the gap between community health services and hospital-based care.

How CBOs can help patients get treatment:

- **Maintain a high profile in the community.** This can help build relationships and influence doctors and others in the medical community to serve those who can not afford treatment. Talking to the media can also help get your message out, said de

Córdova-Hanks.

- **Pair lay health workers with patients.** Many patients who are referred to hospitals for treatments don’t go because they are unfamiliar with the health care system. Community lay workers, volunteers, or case workers can accompany patients to the hospital to increase the chances they will stay in treatment.
- **Use enrollment specialists.** Denver Health helps the uninsured find options. “We have an enrollment specialist who is familiar with programs like Medicaid, the State Children’s Health Insurance Program, state indigent care programs, and private insurance. Shea suggests having the enrollment specialist help patients fill out the forms for these programs. “We found that approval rate jumped from 30 to 80 percent when we helped patients fill out the forms instead of sending them to state offices,” he said.

For more information on Denver Health, contact: (303) 436-6000. ❖

Latest News in NCI Cancer Research

- **New Technologies.** The Cancer Genome Anatomy Project will allow scientists to understand the nature of each person’s cancer. The project is designed to define the particular patterns of genetic changes determining behavior of a particular cancer in an individual, how fast it grows, whether it will spread, and whether it will respond to treatment. The definition of the nature of a particular cancer could lead to revolutionary approaches to early detection, more accurate diagnosis, and more successful treatment.
- **New Drug Treatments.** Scientists are now working to see if a virus that grows only in cancer cells will infect and kill tumor cells without harming normal cells. These and other potential cancer treatments, such as immunotoxins, antisense technologies, and oncolytic viruses, are being readied or are already being tested in patients.
- **New Information System.** An information system will link NCI, the Food and Drug Administration (FDA), pharmaceutical companies conducting new cancer treatment studies, all of the nation’s cancer centers, and the thousands of hospitals and nearly 10,000 doctors participating in cancer research. The system will work to speed up research by enhancing the consistency of reporting study results, and will provide researchers with instant access to the latest data. Enhanced research reporting will, in turn, support FDA’s new drug approval process. The initiative will also make information about the prevention, detection, and treatment of cancer available to everyone.
- **New Clinical Trials Web Site.** CancerTrials can be found at <http://cancertrials.nci.nih.gov>. Maintained by NCI, the site provides educational information and news about ongoing and completed cancer clinical trials in order to help people make informed decisions about joining clinical trials.

For more information on any of these briefs, call NCI at (800) 4-CANCER. ❖

Cancer Information Service (CIS)

National Cancer Institute, National Institutes of Health
(800) 4-CANCER
<http://cis.nci.nih.gov>

Provides information on the latest in cancer news, facts, and research. Free resources and publications.

Centers for Disease Control and Prevention

Division of Cancer Control and Prevention

4770 Buford Highway, NE MS K-64
Atlanta, GA 30341-3717
(888) 842-6355 or (770) 488-4751
<http://www.cdc.gov/cancer>

Indian Health Service

Division of Community and Environmental Health Cancer Programs
5300 Homestead Road, NE
Albuquerque, NM 87110
(505) 248-4132
<http://www.ihs.gov>

Minority Resources

African American Breast Cancer Alliance

P.O. Box 8981
Minneapolis, MN 55408
(612) 825-3675

Association of Asian Pacific Community Health Organizations

1440 Broadway, Suite 510
Oakland, CA 94612
(510) 272-9536
<http://www.aapcho.org>

Cancer Information Resource Center and Learning Exchange (Native C.I.R.C.L.E.)

Charlton 6, Room 282
200 First Street, SW
Rochester, MN 55905
(877) 372-1617
<http://www.mayo.edu/nativecircle>
Provides brochures, videos, online resources guide, and speakers bureau.

Howard University Cancer Center

2041 Georgia Avenue, NW
Washington, DC 20060
(202) 806-7697
<http://www.huhsosp.org>

Intercultural Cancer Council

Baylor College of Medicine
1720 Dryden, PMB-C
Houston, TX 77030
(713) 798-4617
<http://icc.bcm.tmc.edu>

National Alliance for Hispanic Health

1501 16th Street, NW
Washington, DC 20036-1401
(202) 387-5000
<http://www.hispanichealth.org>
Runs the National Hispanic Colorectal Cancer Outreach and Education Program

Associations and Organizations

The Alliance for Lung Cancer

P.O. Box 849
Vancouver, WA 98666
(800) 298-2436; (360) 696-2436
<http://www.alcase.org>

American Cancer Society

1599 Clifton Road, NE
Atlanta, GA 30329-4251
(800) 4-CANCER
<http://www.cancer.org>

American College of Obstetricians and Gynecologists

409 12th Street, SW
PO Box 96920
Washington, DC 20090-6920
<http://www.acog.org>
Provides information on cancers of the ovary, uterus, vulva, and cervix.

Cancer Care, Inc.

275 7th Avenue
New York, NY 10001
(800) 813 4673
<http://www.cancercare.org>
Provides financial assistance, referrals, and information on cancer and treatments.

Colon Cancer Alliance

175 Ninth Avenue
New York, NY 10011
(212)627-7451; toll free (877)-422-2030
<http://www.ccalliance.org>

Kidney Cancer Association

1234 Sherman Avenue, Suite 203
Evanston, IL 60202-1375
(800) 850-9132
<http://www.nkca.org>

Leukemia and Lymphoma Society of America

600 3rd Avenue
New York, NY 10016
(800) 955-4572
<http://www.leukemia-lymphoma.org>
Provides grant information and education materials and publications

National Alliance of Breast Cancer Organizations (NABCO)

9 East 37th Street, 10th Floor
New York, NY 10016
(212) 889-0606
<http://www.nabco.org>

National Children's Cancer Society

1015 Locust, Suite 600
St. Louis, MO 63101
(800)-532-6459
(314) 241-1600
<http://www.children-cancer.org>
Provides financial assistance.

National Patient Advocate Foundation/ National Managed Care Resource Network

753 Thimble Shoals, Suite B
Newport News, VA 23606
(800) 532-5274
<http://www.patientadvocate.org>
Provides referral services to patients in need of support in negotiating state and national public assistance programs.

Us Too International, Inc.

930 North York Road, Suite 50
Hinsdale, IL 60521
(800) 80-USTOO
(630) 823-1002
<http://www.ustoo.com>
Provides information on prostate cancer.

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of Public Health and Science
Office of Minority Health Resource Center
P.O. Box 37337
Washington DC 20013-7337

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Closing the Gap

Conferences: Year 2000

Aug 31-Sept 1: *The Role of Nutrition in Preventing and Treating Breast and Prostate Cancer.* American Institute for Cancer Research (AICR) 10th Annual Research Conference, Mayflower Hotel, Washington, DC. Contact, AICR, (202) 328-7744; or e-mail research@aicr.org.

Sept 8-9: *Living Fully With Cancer 12th Annual Conference*, sponsored by the M.D. Anderson Cancer Center. Houston Marriott Westside Hotel in Houston, TX. For registration information, contact: Anderson Network, (800) 345-6324.

Sept 7-9: *Association of Pediatric Oncology Nurses (APON) 24th Annual Conference.* Sponsored by APON. Wyndam Palace Resort and Spa, Orlando, FL. Contact: APON, (847) 375-4724; or e-mail info@apon.org.

Oct 2-4: *Cancer Vaccines 2000: Cancer Research Institute International Symposium.* Sponsored by CRI. Manhattan Conference Center, New York City. Contact: Mary MiCari, CRI, (212) 688-7515 or e-mail events@cancerresearch.org.

Oct 19-20: *Cancer Survivorship Throughout the Lifespan: Challenges for the 21st Century.* Presented by Tomorrows Children's Fund, NJCCR. Trump Plaza Hotel and Casino, Atlantic City, NJ. Contact: Michael Toleno, New Jersey Commission on Cancer Research, (609) 633-6552.

Oct 29- Nov 2: *Unmet Medical Needs: Therapies for the New Millennium.* American Association of Pharmaceutical Scientists 2000 Annual Meeting at Indiana Convention Center, Indianapolis, IN. Call AAPS, (703) 243-2800; or e-mail meetings@aaps.org.

Nov 2-5: *American Association for Cancer Education (AACE) & European Association for Cancer Education (EACE) Joint Meeting.* Wyndham City Center Hotel, Washington, DC. Call Virginia Krawiec, AACE, (404) 329-7612; or e-mail gkrawiec@cancer.org.

Nov 16-17: *President's Cancer Panel.* Vanderbilt Cancer Center. Sponsored by the National Cancer Institute. Nashville, TN. Call NCI at (301) 496-1148; or e-mail wilsonm@31b4.nci.nih.gov.

Useful Web Sites

- *Cancer Clinical Trials Web site:* http://cancertrials.nci.nih-gov/system/index_new.html This is a new site from NCI, which is revamping how it develops, reviews, conducts, and supports clinical trials. EPP and the National Network of Physician Specialists (see p. 12) are a part of this effort.
- *Cansearch:* <http://www.cansearch.org/canserch/canserch.htm>. Produced by the National Coalition for Cancer Survivorship to provide survivors and patients with a step-by-step guide to cancer resources found on the Web.
- *National Foundation for Cancer Research.* <http://www.nfcr.org/html/homepage/index.html> NFCR's Web site is devoted to providing information about prevention, detection, and treatment of cancers, as well as up-to-date content in the fields of research for a cancer cure. ❖