

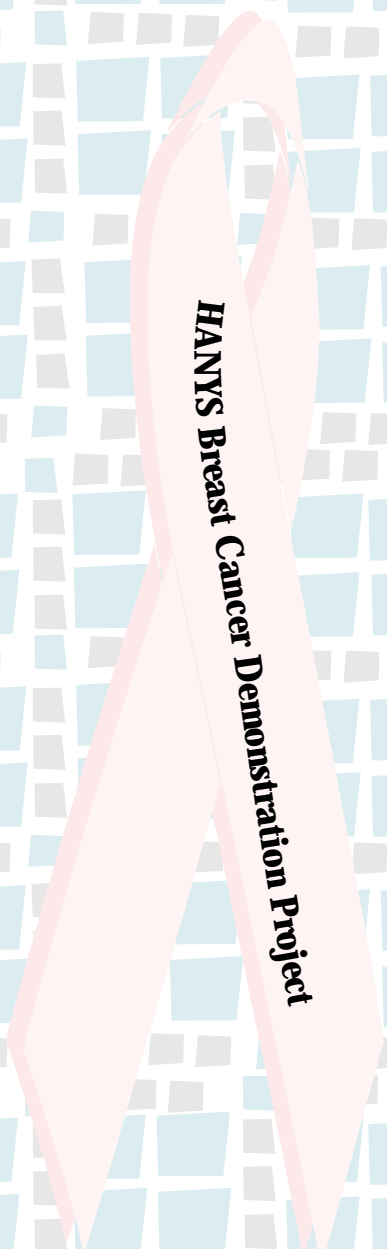
## LOOKING FORWARD: HANYS BCDP PARTICIPANT HOSPITALS CONTINUE TO BUILD ON ACCOMPLISHMENTS

Since 1998, the Healthcare Association of New York State (HANYS) Breast Cancer Demonstration Project (BCDP) has been researching and developing an integrated model for comprehensive breast health services. The Project was created by HANYS with funding provided by the New York State Assembly as part of the state budget, to develop a model for comprehensive breast health services that supports a coordinated way of caring for patients with breast cancer. The model is being designed to increase access to and decrease fragmentation of services and to improve patient education and the standard of care. Once developed, HANYS will disseminate the model to member hospitals across New York State. This year's funding will allow the continuation of hospital-based quality improvement activities, development of organizational measures, and evaluation of performance indicators.

HANYS BCDP participants have created partnerships that are reflective of the breast health care needs of all residents of New York State, ranging from community outreach to clinical integration and compassionate end-of-life care. In the past year, our participant hospitals have conducted innovative projects in several areas including: translation of breast cancer education materials into foreign languages; establishment of patient navigation programs and multi-disciplinary teams; and development and implementation of service monitoring systems. (Several of these initiatives have been described in earlier editions of Mosaic.) Currently, HANYS BCDP is assembling recommendations for a core set of patient education materials that can be tailored to meet the needs of individual patients and facilities. Once the Advisory Board concludes its final assessment and recommendations for the core set, HANYS will make it available to our member hospitals.

This year, HANYS BCDP participants will complete the design of the model for comprehensive breast health services. Selected model components piloted at demonstration sites are being tailored to meet the specific needs of individual communities and consumers. What is learned from the pilot projects will be shared with our members when the model is disseminated next year.

*HANYS extends its sincere thanks for the participation and contributions of all participant hospitals, Advisory Board members, and partner organizations over the past two years. We especially thank Assembly Speaker Sheldon Silver and Assemblymembers Richard Gottfried and Helene Weinstein for their ongoing support and commitment to decreasing mortality from breast cancer.*



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## IMPROVING BREAST HEALTH CARE ACCESS AND DELIVERY

In February, HANYS BCDP *Mammography Screening Outreach Development Guide* was distributed in facility-specific editions to the Project's participating hospitals. The Guide is designed to help hospitals develop and improve mammography screening programs by providing them with strategies for outreach program development and opportunities to better understand the breast health consumers in their service areas. The Guide supports HANYS BCDP hospitals in their efforts to improve breast health care access and delivery, especially in areas where there is low utilization and high risk for breast cancer.

### How was the Guide Developed?

The *Guide* resulted from the HANYS BCDP Advisory Board's work examining breast cancer issues, screening behavior, and preferences of women at risk for breast cancer in New York State. Breast cancer risk in this context has been defined in terms of incidence and mortality, acknowledging that lower incidence rates sometimes coexist with higher mortality rates, particularly among minority populations, who frequently enter the health care delivery system at a more advanced stage of disease<sup>1</sup>. HANYS staff developed the *Guide* collaboratively with HANYS Services, Inc. (HSI), the association's subsidiary that provides a broad range of comprehensive performance improvement products and consulting services for health care providers.

### Data Sources and Methodology

The *Guide* uses nationally recognized data sources and marketing techniques including the MEDSTAT Group's PULSE Health Care Research Survey, PRIZM Lifestyle Segmentation System, Claritas Demographics, and Simmons Market Research Bureau information, all incorporated into HSI's FACETS™ Information Program software. The National Cancer Institute's Consumer Health Profiles are used to describe the lifestyles of households at risk for breast cancer.

### What does the Guide Do?

The *Mammography Screening Outreach Development Guide* is designed to assist in developing or improving a mammography screening outreach program tailored to the demographic characteristics of the neighborhoods in a hospital's service area. The *Guide* locates households at risk for breast cancer by neighborhood, describes them in a

series of maps and reports, and presents customized communication strategies to increase mammography screening rates in those neighborhoods. Included with the *Guide* are two publications that offer additional strategies for increasing breast cancer screening rates. They are the National Institute of Health's book *The Picture of Health – How to Increase Breast Cancer Screening in Your Community* and the BCDP's *Breast Cancer Free Education and Outreach Tools Manual*.

### How Does the Mammography Outreach Guide Work?

- Locates women at risk for breast cancer by neighborhood in a hospital's service area.
- Describes their demographic characteristics.
- Identifies effective, customized communication strategies to reach these at risk women and increase their mammography screening rates.
- Provides a step-by-step description of activities, information, and tools that can be included in the outreach program development process.

**For more information on obtaining similar data for your facility, please contact Peter Avvento of HANYS Services, Inc. at (518) 431-7920.**

### What has the HANYS BCDP Learned From the Guide?

HANYS staff has applied the *Guide's* methodology to HANYS BCDP participant hospitals' data. The analysis of 1998 data showed that in households at risk for breast cancer, a large majority of women neither had a mammogram at a hospital nor received a physician referral for a mammogram. For women 65 and over, the analysis revealed that a significant percentage did not have a mammogram in 1998 because they believed they did not need one. Since research demonstrates that the primary factor motivating women to access mammograms is physician referral, this analysis indicates opportunities for further physician and patient education.

<sup>1</sup> Identified demographic risk factors for breast cancer include: female over age 40, poverty (as defined by national poverty guidelines for family of 4), low education level (less than 12 years of education), membership in specific racial groups (Asian-Pacific Islander, Black Non-Hispanic, Hispanic).

## BREAST CANCER OUTREACH EFFORTS CONTINUE

At its June 6 meeting, the HANYS BCDP Advisory Board discussed a broad range of issues including outreach program development, palliative care, the possible development of breast cancer performance measures by the Joint Commission on Accreditation of Health Care Organizations (JCAHO), and survey development and piloting. The Advisory Board also decided to form a Patient Navigator work group.

### ■ OUTREACH DEVELOPMENT

Use of Mammography Screening Outreach Development Guide

HANYS staff explained the usefulness of the *Mammography Screening Outreach Development Guide* (see related article on page 2). The National Cancer Institute, among others, successfully uses its nationally recognized methodology. Staff described how the *Guide* could help hospitals develop and improve mammography screening programs.

Education and Outreach Tools Manual

The HANYS BCDP Outreach and Education Committee described the progress of the *Breast Cancer Free Education and Outreach Tools Manual*. The draft manual was mailed to Project hospitals in May for multi-disciplinary and patient focus group review. It was designed in response to HANYS BCDP Advisory Board members' needs for additional education and outreach resources for breast health programs. It is intended to help standardize the breast cancer information distributed to women and will be made widely available to HANYS member hospitals when published in its final form. It includes resources to help women of different languages, varying literacy levels, and cultural backgrounds. Although HANYS does not have additional copies, all of the materials are available to individuals without charge from the sponsoring organizations.

### ■ PALLIATIVE CARE

Integrating Palliative Care into Breast Cancer Services

Robert D'Antuono, Deputy Director of the Center to Advance Palliative Care at Mount Sinai School of Medicine was a featured speaker at the Advisory Board meeting. Mr. D'Antuono expects that a palliative care "how-to" manual will be available by the end of this year. An interactive Web site is also in development. More detailed information regarding his presentation is contained on page 4.

### ■ JCAHO PERFORMANCE MEASURES

Potential Development of Breast Cancer Measures

The JCAHO has put forth a number of possible performance measurement areas that accredited organizations would be required to select from for future data collection, including breast can-

cer. Although the measures related to breast cancer would not be required for several years, HANYS staff will keep the Advisory Board apprised of the JCAHO's plans and will solicit feedback on specific breast cancer measures if they are made available for review.

### ■ HANYS BCDP SURVEYS

Patient Satisfaction Survey

The Clinical Medical Work Group is refining a patient satisfaction instrument that will be used as a quality measure in hospital breast health programs. The overall goal is to better understand the satisfaction level and experience of under-served and minority patients receiving services at HANYS BCDP hospitals. Factors incorporated in the instrument will include motivation to access care, interactions with health care staff, information needs, non-medical barriers, and secondary follow-up. Implementation of the survey is planned for September.

Mammography Reimbursement Survey

The HANYS BCDP Systems Work Group continues its work on a survey to evaluate the impact that Medicare reimbursement rates have on hospital provision of effective mammography screening services. The focus of this inquiry is to identify and assess gaps between facility costs and Medicare reimbursement rates for both screening and diagnostic mammography. It is believed that Medicare rates may be inadequate and that organized input from the hospitals is needed to demonstrate concerns. The survey is currently being administered to HANYS BCDP hospitals.

### ■ Patient Navigation Work Group

The HANYS BCDP Advisory Board has established a new Patient Navigator Work group to share information and facilitate staff development. Patient navigators support patients throughout the continuum of care as information resources and points of contact, helping to bridge gaps that can occur in care. They have played a significant role in advancing the HANYS BCDP's goals of increasing patient access to care and decreasing fragmentation of services.

The work group will provide an educational and supportive forum for patient navigators. Brenda Poignard Blane, M.Ed., Associate Director of the Cancer Control Center of Harlem Hospital and Chair of the newly formed group, referred to patient navigators as "social advocates" and stressed their multi-faceted approach to ensuring continuity and coordination of care.

Patient navigator programs in New York State have achieved national attention and have been credited with decreasing length of stay, increasing compliance, removing barriers to care, and enfranchising patients. For more information on patient navigation in breast cancer services, please refer to the January 2000 issue of *Mosaic*®.

## CENTRALLY MANAGED EVALUATION SYSTEM

One of HANYS' roles in the HANYS BCDP is to help the Project's hospitals with cancer service improvement activities and initiatives. This year, the major goal of HANYS BCDP is to design a model for integrated breast health services, incorporating what we learn from our participants' site-based activities.

A primary focus in model development is designing a centrally managed evaluation system built on work already accomplished. Advisory Board members have identified a strong need for tools to measure and manage patient outcomes specific to the breast care continuum. (Under consideration are tools and strategies that hospitals and networks may use with existing resources to evaluate their own systems and as benchmarks for improvement.)

### EVALUATION CATEGORIES

- access
- case management
- clinical pathology
- compliance with standards
- coordination
- patient education
- patient satisfaction
- staff education
- system process components
- utilization

The integrated model will have an evaluation system incorporating these general categories.

Rather than prescribe a method to achieve system and clinical integration, the model will enable each hospital to determine its focus and indicators of excellence. External measures such as those developed by the American College of Surgeons' Commission on Cancer and other nationally recognized organizations, may help facilities focus on evaluation. Likewise, HANYS BCDP may wish to develop measures to evaluate its own progress.

Two measurement tools – a patient satisfaction survey and a Medicare mammography services and reimbursement survey – are currently developed by the Advisory Board. In addition, HANYS BCDP's *Building Systems of Breast Cancer Care: A Comprehensive Review of Literature and Web Resources*<sup>©</sup> contains sections on quality improvement, measurement tools, and data management. Additional quality improvement tools and resources can be found on HANYS BCDP and Quality Web pages at [www.hanys.org](http://www.hanys.org).

## PALLIATIVE CARE AND BREAST CANCER

Palliative care has been defined as “the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families.”<sup>2</sup>

In recent years, hospitals have begun to explore alternatives to improve their end-of-life services, understanding that the needs of dying patients and their families differ substantially from the needs of hospital patients seeking curative care. With roots in the hospice movement, palliative medicine deals with alleviating the suffering of patients with chronic, acute, or terminal illness. Palliative medicine combines the science of pain and symptom management with an emphasis on emotional and spiritual matters to reach beyond the traditional realm of medicine.

Many health care providers recognize that the growing population of aging New Yorkers with chronic disease has increased the need to incorporate palliative care in acute care settings. In 1996, the United Hospital Fund's Hospital Palliative Initiative explored the status of end-of-life-care in New York City hospitals and called for integrating well-defined palliative

models within clinical routines. It also recommended incorporating clinical services and procedures for coordinating the use of these models.

<sup>2</sup> Technical Report Series 804, Cancer Pain and Palliative Care. Geneva: World Health Organization 1990:11.

### PALLIATIVE CARE PROGRAM PRECEPTS

The Center to Advance Palliative Care's philosophy is to:

- affirm life and regard dying as a normal process;
- neither hasten nor postpone death;
- foster opportunities for growth at the end of life; and
- help patients live as actively as possible until death.

Precepts include:

- respect of patients' goals, preferences, and choices;
- provision of interdisciplinary, integrated, comprehensive care – physical, psychological, social and spiritual;
- support for family and other caregivers' concerns through the patients' illness, death, and bereavement; and
- seamless integration of palliative care within the structure of hospitals and health systems.

## RELATED PUBLICATIONS OF INTEREST

### ***Disease Management is the Future: Breast Cancer is the Model***

This article describes how variations in procedures and pathways in the breast care continuum may lead to significant differences in patient experiences and health care costs. It details how a breast center is uniquely positioned to develop disease management for the breast, including sub-specialized care, adoption of evidence-based protocols, and comprehensive management of outcome information. The authors state that this disease management approach may increase the quality of patient care, decrease the overall cost of breast cancer, and increase reimbursement and practice satisfaction for breast physicians.

Kolb GR. *Surg Oncol Clin N Am* 2000 Apr;9(2):217-32

### ***Unifying Organizational Approaches to Measuring and Managing Patient Outcomes***

Information about patient outcomes is increasingly available to guide consumers in their selection of health care. This article states that by unifying programs of performance improvement, case management, and research, health care providers may take control of care processes and outcomes. It provides four case studies of patient care improvements achieved using this unified approach.

Nolan MT. *Journal of Nursing Administration* 2000 Jan;30(1):27-33

### ***Guide to Choosing Technology to Support the Measurement of Patient Outcomes***

This article describes how health care providers can choose technologies including personal computers, scanning systems, and hand-held computing devices for multidisciplinary groups charged with improving the quality and cost-effectiveness of patient care. Three types of patient data management technologies are reviewed and questions executives may have in selecting systems for their departments are answered.

Johnson C. *Journal of Nursing Administration* 2000 Jan;30(1):21-6

### ***Important Attributes of Quality Health Care: Consumer Perspectives***

This study examined the importance to consumers of attributes of health care quality and nursing care quality. It found that the most important indicators of high-quality nursing care to consumers were: being cared for by nurses who are well trained; being able to communicate with the nurse;



spending enough time with the nurse; having a nurse teach them about the illness, medications, treatments, and staying healthy; and being able to call a nurse with questions. The study emphasized the importance that consumers place on teaching by the nurse, particularly among people with less education, low-income levels, and chronic illnesses.

Oermann MH. *Journal of Nursing Scholarship*, 2000;32(2):167-72

### ***Methodology for Targeting Physicians to Improve Breast Cancer Screening***

This article describes a method for identifying physicians who do not adhere to breast cancer screening recommendations or are in need of continuing medical education, and ways to target educational interventions for those with patients who underuse mammography.

Lane DS. *American Journal of Preventative Medicine* 1999 May;16(4):289-97

### ***Measuring Health Care Quality: Breast Cancer***

This paper summarizes commonly used quality measures for breast cancer in the following areas: health outcomes, disease progression and management, performance of essential care processes, disruption to patient or family routine, and satisfaction with care. It also provides recommendations for measurement of health outcomes, including quality of life, and recommendations for outcomes for processes of care.

U. S. Department of Health and Human Services. (1996). (AHCPR Publication No. 96-N020). Rockville, MD: Author

# What's Helpful on the Web?

You can access these and other resources on the BCDP Web page at [http://www.hanys.org/tools/Breast\\_Cancer\\_Project/links.htm](http://www.hanys.org/tools/Breast_Cancer_Project/links.htm)

## QUALITY IMPROVEMENT AND MEASUREMENT WEB SITES

### BENCHMARKING AND BEST PRACTICES NETWORK

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#### [www.benchnet.com](http://www.benchnet.com)

This site offers a comprehensive, specialized forum for all phases of benchmarking that is designed for veteran practitioners as well as novices.

### NATIONAL ASSOCIATION OF HEALTH DATA ORGANIZATIONS (NAHDO)

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#### [www.nahdo.org/nahdo/index.html](http://www.nahdo.org/nahdo/index.html)

NAHDO is dedicated to improving health care through the collection, analysis, dissemination, and use of health care data. It works with state, federal, and private sector technical and policy leaders and consultants to expand health systems development and shape responsible health information policies.

### U.S. FOOD AND DRUG ADMINISTRATION (FDA) MAMMOGRAPHY PROGRAM WEB SITE

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#### [www.fda.gov/cdrh/mammography](http://www.fda.gov/cdrh/mammography)

This FDA site provides information about quality standards required for all facilities performing mammograms. The site includes extensive information on the Mammography Quality Standards Act and also answers a variety of frequently asked questions about mammography and FDA certified mammography locations. It includes the Mammography Site Database search engine. Individuals may search for a nearby FDA certified mammography facility by entering their state and zip code.

### AGENCY FOR HEALTH CARE RESEARCH AND QUALITY (AHRQ)

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#### [text.nlm.nih.gov/ftsr/pick?collect=ahcpr&dbName=0&cc=1&t=906650929](http://text.nlm.nih.gov/ftsr/pick?collect=ahcpr&dbName=0&cc=1&t=906650929)

The AHRQ site (formerly AHCPH) contains clinical practice guidelines, quick reference guides for physicians, and patient's guides for quality mammography and management of cancer pain (in English and Spanish). All publications are downloadable.

### BEST PRACTICE NETWORK

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#### [www.best4health.org](http://www.best4health.org)

The Best Practice Network has a variety of resources that focus on best practice development and implementation. Many articles, presentations, and interviews are downloadable.

## WEB SITES FOR MINORITY POPULATIONS

### OFFICE OF MINORITY HEALTH RESOURCE CENTER

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#### [www.omhrc.gov/frames.htm](http://www.omhrc.gov/frames.htm)

The OMHRC Web site contains information for minorities on breast cancer including fact sheets, toll-free phone numbers, breast health resources, and links to other organizations. A *Breast Cancer Resource Guide for Minority Women* can be downloaded at the "Publications" link.

### CELEBRATING LIFE

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#### [www.celebratinglife.org/home.htm](http://www.celebratinglife.org/home.htm)

Celebrating Life is a national foundation that promotes breast cancer awareness specifically among African American women and women of color. This site includes information to encourage and support the advancement of knowledge and awareness of breast cancer risk and prevention in the African American community and for women of color.

### NATIONAL ASIAN WOMEN'S HEALTH ORGANIZATION (NAWHO)

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#### [www.nawho.org/program/bccframe.html](http://www.nawho.org/program/bccframe.html)

NAWHO's National Plan of Action on Asian American Women and Breast Cancer provides critical recommendations for increasing the participation of Asian American women in breast cancer research, outreach and education programs, and advocacy efforts. This site provides information on NAWHO initiatives, advocacy, publications, and more.

### BREAST CANCER IN MEN

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#### [www.interact.withus.com/interact/mbc/about.htm](http://www.interact.withus.com/interact/mbc/about.htm)

This site is for people dealing with male breast cancer including men suffering from this disease, physicians, and researchers.

### BCDP ADVISORY BOARD CHAIR RECEIVES LASKER AWARD

Harold P. Freeman, M.D., President and Chief Executive Officer of North General Hospital in Harlem and Advisory Board Chair of the HANYS BCDP, has received the prestigious Lasker Award for Public Service in Support of Medical Research and the Health Sciences. The Lasker Award, presented in Washington, D.C. on May 9, honors an exceptional contribution that sustains and enhances the nation's commitment to medical research.

Dr. Freeman was honored for advocacy efforts that have "broadened society's understanding of and attention to significant issues of public health." He was cited for "enlightening health care providers and the public about the relationship between race, poverty, and cancer" and for devoting "his life's work to addressing the injustices and discrimination imposed upon minority communities by the health care system."

Dr. Freeman is considered a national leader in education and an accomplished researcher and authority on the relationship between race, poverty, and cancer. During his career he has served as President of the American Cancer Society and as Director of Surgery at New York's Harlem Hospital Center. Dr. Freeman is currently President of President Clinton's Panel on Cancer.

*Integrating Palliative Care continued from page 4*

At its June 6 meeting, the HANYS BCDP Advisory Board emphasized the importance of palliative care in breast cancer treatment. Guest speaker Robert D'Antuono, Deputy Director of Mount Sinai's Center to Advance Palliative Care, presented "Integrating Palliative Care into Breast Cancer Services." Mount Sinai's Center, established by the Robert Wood Johnson Foundation, hopes to promote wider access to high-quality palliative care in hospitals and health systems nationwide. Its goal is to increase the number of people dedicated to improving quality end-of-life care by assisting hospitals and health systems in the development of palliative care programs. The Center is located at the Mount Sinai School of Medicine in New York and its Web site is [www.capcmssm.org](http://www.capcmssm.org).

## News

### FROM THE HANYS BCDP SITES

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**F.F. Thompson Hospital:** In the short time since its opening, the Sands Cancer Center, a collaboration of Thompson Health in Canandaigua and Strong Memorial Hospital in Rochester, has greatly impacted breast care in the Canandaigua area. New modalities include on-site radiation and chemotherapy, a lymphedema program, complementary and alternative therapies, and the addition of a tumor registrar.

**Harlem Hospital Cancer Center:** A bilingual physician's assistant has been added to the Center's staff to expand services in the cancer clinic to include pap smears and clinical breast examinations. A new cancer registry in Harlem's Cancer Center will allow cancer follow-up services to extend beyond traditional diagnosis and treatment to lifetime follow-up. Patient navigation continues to be a model program at the center and was recently filmed by an independent film producer for a PBS television documentary that will be aired through Howard University in April 2001. The program, "A Celebration of Life," features an interview with a cancer patient who received navigation services, a patient receiving a clinical breast exam, and a patient interview with a radiologist. In addition, the University of California has asked to use the Harlem Patient Navigation Program as a comparison model in its evaluation of a similar program.

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*Web sites for Minority Populations continued from page 6*

#### THE MAUTNER PROJECT FOR LESBIANS WITH CANCER

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##### **[www.mautnerproject.org](http://www.mautnerproject.org)**

The Mautner site provides direct services to lesbians with cancer, their partners and caregivers; education and information to the lesbian community about cancer; education to the health care community about the special concerns of lesbians with cancer and their families; and information about advocacy on lesbian health issues. The site is available in English and Spanish.

#### YUPI SALUD - BREAST CANCER RESOURCES IN SPANISH (WEBSITES DEL CÁNCER DE MAMA EN ESPAÑOL)

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##### **[www.yupi.com/Categorias/Salud/Enfermedades/Cancer/Mama](http://www.yupi.com/Categorias/Salud/Enfermedades/Cancer/Mama)**

Yupi Salud provides resources on breast cancer in Spanish. Topics include basic information on breast cancer (cancer de mama), mammography (mamografía), diagnosis (diagnóstico del cáncer de mama), treatment options, breast cancer surgery (cirugía del cáncer de mama), breast implants, and more.

News from the BCDP Sites continued from page 7

**Long Island College Hospital:** The newly developed patient navigation initiative at Long Island College Hospital has been particularly successful in the areas of patient education and in decreasing length of stay. Focusing on follow-up and compliance, the patient navigator is developing new computer skills that will allow for enhanced tracking of patient outcomes.

**Lutheran Medical Center:** A Women's Health Awareness Day was held at the Park Ridge site featuring a lecture series, information, and clinical breast examinations. A patient navigation program commenced in June 2000, and the Medical Center is also developing an architectural plan for a new woman's health center.

**New York Community Hospital of Brooklyn:** On July 15, the patient navigation program officially began. The patient navigator will schedule procedures, initiate follow-up telephone calls, and process reports with the goal of moving women through the breast care process with care, dignity, and professionalism.

**New York Medical Center of Queens:** Outreach efforts to the Asian-American population have been extremely

successful, in part due to alliances formed with the local American Cancer Society. Written materials have been translated into several Chinese dialects and the Breast Center has been featured at local support group meetings in the Asian community. Cancellation rates at the center have dramatically decreased.

**North General Hospital:** The hospital is the recipient of a \$5 million gift from designer Ralph Lauren to help establish a cancer prevention and treatment center in cooperation with Memorial Sloan-Kettering Hospital, also in Manhattan. One goal of the proposed cancer center will be to address research demonstrating large disparities in cancer detection and survival rates between blacks and whites.

**North Shore-Long Island Jewish Health System:** The system is holding Breast Tumor Board conferences and is planning to hold teleconferences in the near future. The conferences involve different disciplines presenting cases at each meeting, and include plans to discuss relevant issues such as ongoing or future clinical trials and sentinel node biopsy.

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