

HANYS Breast Cancer Demonstration Project Web Page is now available.

The Healthcare Association of New York State's (HANYS) Web site now includes a page devoted entirely to the Breast Cancer Demonstration Project (BCDP). The BCDP Web page provides an overview of the project's activities and goals, participant hospitals, and advisory board. The site includes a project newsletter archive and, as requested by the BCDP Advisory Board, a listing of annotated links to other breast cancer Web sites. The address is: www.hanys.org/tools/Breast_Cancer_Project/breast_cancer_project.htm.

The page was designed with the help of the BCDP Advisory Board. Its primary goal is to provide information about the development of a BCDP network model for treating breast cancer. The page is intended for BCDP participants and HANYS members, health care providers and researchers, and breast cancer patients and family members.

The breast cancer links are organized by subject areas that include best practices, clinical guidelines, cancer research journals, cancer resources, patient decision-making tools, and survivorship. Descriptions indicate whether the site is designed primarily for health care providers or for patients and the general public. Additionally, the page has a special section listing sites available in both English and Spanish. We hope that users will find the BCDP Web Page a useful resource. HANYS welcomes and encourages your comments and questions regarding the BCDP Web Page.

In this Issue:

<i>BCDP Web Page Now Available</i>	Cover
<i>BCDP Begins Model Development</i>	2
<i>Advisory Board Meets</i>	2
<i>IOM Cancer Care Report Recommends Practice Guidelines</i>	4
<i>What's Helpful on the Web</i>	4
<i>News from the BCDP Sites</i>	5
<i>New BCDP Director</i>	6

The Breast Cancer Demonstration Project

BCDP BEGINS MODEL DEVELOPMENT

What is the best model of breast cancer care? There are more published guidelines about breast cancer treatment and management than for any other type of cancer. Guideline sources include the government, medical specialty societies, national cancer organizations, research groups, hospitals, and health plans.

The BCDP is reviewing breast cancer standards and guidelines to better understand their recommendations and objectives. This guideline project is divided into three distinct phases: research, analysis, and conclusions with recommendations. The project is identifying common themes in the guidelines and is working to understand how the themes may be incorporated into a model of breast cancer care.

To date, the following themes have been identified:

- ◆ Approach breast cancer as a chronic disease.
- ◆ Use multi-disciplinary teams for breast cancer diagnosis and treatment, and program management and evaluation.
- ◆ Provide physician and staff education on breast cancer.
- ◆ Use a cancer registry and specialized information systems.
- ◆ Adhere to evidence-based protocols.
- ◆ Participate in research protocols.
- ◆ Use standardized data collection to track performance and outcomes.
- ◆ Provide feedback on performance.
- ◆ Plan quality improvement.
- ◆ Standardize care.
- ◆ Increase and improve patient outreach and education.
- ◆ Involve patients in treatment planning, supportive services, and program evaluation.

The BCDP recognizes that evidence to support guidelines can vary. When reviewing guidelines, there are two guiding questions: “What are the goals for each guideline?” and “How can the guidelines be integrated into the BCDP goal of creating consistent, integrated, clinically- and culturally-appropriate services for breast cancer patients?”

These themes reflect the concerns of patients, providers, researchers, payers, and purchasers. They provide a context to make recommendations for elements of a project model. Later in the project, the BCDP anticipates providing information about organizational strategies for incorporating the themes and recommended elements into breast cancer programs.

ADVISORY BOARD MEETS

The BCDP Advisory Board met on February 25. A wide variety of topics were discussed, including:

- ◆ national perspectives on cancer policy,
- ◆ national breast cancer guidelines,
- ◆ availability and review of education and outreach tools,
- ◆ the BCDP Mammography Outreach Program Development Guide developed in conjunction with HANYS Services, Inc. (HSI), and
- ◆ development of a patient satisfaction tool.

Breast Cancer Recommendations and Guidelines

Project staff presented a summary of national perspectives on cancer policy, breast cancer guidelines, and BCDP activities.

continued on page 3

ADVISORY BOARD MEETS *continued from page 2*

Dr. Harold Freeman, BCDP Board Chair and member of the President's Cancer Panel, discussed the Panel's 1998 Annual Report, *Cancer Care Issues in the United States: Quality of Care, Quality of Life*. He provided many insights about the use of guidelines and reiterated the Panel's cautions that guidelines that are too rigid or narrow can pose a barrier to clinical innovation, effective care, and/or reimbursement. He said the panel held discussions about payers and others reimbursing for clinical trials in order to increase participation, and is optimistic that this concept may be adopted for some government peer-reviewed clinical trials.

Dr. Freeman addressed the important distinction between quality of care and quality of life. Quality research, scientific definitions of quality, and health care delivery must be balanced with individual ethnic, racial, and cultural preferences and beliefs. The BCDP Advisory Board will continue to explore the various guidelines and recommendations in developing a model of breast cancer care. The goal is to identify essential elements and understand their applicability to the BCDP model development.

Research must address survivorship issues including long-term effects of treatment, family issues, socioeconomic impacts of disease, and employability.

The Board also discussed *Themes from the Guidelines*, a BCDP working paper.

Education and Outreach Resource List

Board members had an opportunity to view sample copies of items on the Breast Cancer Education and Outreach Tools Resource List. The list was developed by the Outreach and Education Subcommittee in an effort to standardize core information that is distributed to breast health patients. All of the materials on the list are available without charge. The subcommittee and staff are seeking appropriate Asian language breast health materials. The final listing will be provided to all HANYS member hospitals and made available to the public through the BCDP Web page.

Patient Satisfaction Instrument

Board members reviewed a patient satisfaction instrument that is being developed by the Clinical/Medical Subcommittee for use in hospital breast health programs.

The goal is to understand the satisfaction level and experience of under-served and minority patients receiving mammography services at BCDP hospitals. The instrument covers:

- ◆ motivation to access care,
- ◆ interactions with health care staff,
- ◆ information needs,
- ◆ non-medical barriers, and
- ◆ secondary follow-up.

The instrument will contain questions specific to different cultural populations. The patient satisfaction instrument will be completed by September 2000.

Mammography Outreach Guide

The BCDP Advisory Board, Project staff, and HANYS Services, Inc. have been collaborating to provide facility-specific information to help with mammography outreach. The BCDP Data Project uses current program experience and expert advice from project participants, risk factors are identified and analyzed using sample survey data and census tract data. The lifestyles of households projected to be at-risk populations are described in detail, providing baseline data to measure change in breast health screening utilization over time.

The BCDP Board meeting reviewed the BCDP *Mammography Outreach Program Development Guide*, developed as part of the data project. Using a combination of maps and reports detailing the lifestyles of households at risk for breast cancer, the guide may be used to estimate household health care utilization, identify health behaviors, and target consumers for breast health care, education, wellness, and other programs.

The BCDP *Mammography Outreach Program Development Guide* can help in developing a mammography screening outreach program tailored to the demographic characteristics of the communities in a hospital service area. The guide contains a step-by-step description of the activities, information, and tools that can be included in the development process. For more information on similar data for your facility please contact Dot Jones of HANYS Services, Inc. at (518) 431-7747.

IOM CANCER CARE REPORT RECOMMENDS PRACTICE GUIDELINES

The 1999 Institute of Medicine (IOM) report *Ensuring Quality Cancer Care* recommends the use of systematically developed evidence-based guidelines to improve the quality of cancer care in health care systems. The report detailed mixed experience with oncology practice guidelines changing provider behavior or outcomes and said that physician non-compliance with guidelines can limit consumer access to recommended cancer care. The authors identified limitations in the way guidelines are developed or implemented that can lead to inconsistency in practice and less favorable outcomes.

Evidence shows that guidelines with the greatest likelihood of success include those with:

- ◆ in-house development,
- ◆ specific educational intervention,
- ◆ patient-specific reminders at the time of consultation, and
- ◆ a system to hold the provider accountable for adherence.

Clear benchmarks are needed for facilities to target or implement guidelines. Personal involvement in the process of change encourages adherence, and evidence suggests that physicians are more likely to ascribe credibility to information from sources they know and respect. Guidelines based on empirical data rather than expert opinion are most likely to succeed in influencing provider practices. The report calls for intensive support directed toward these guideline efforts.

Ensuring Quality Cancer Care provides information about several organizations that have developed oncology practice guidelines to promote treatment that conforms to the best medical evidence available. The report also identifies many aspects of cancer care for which evidence is lacking upon which to judge best practice. Additionally, some clinical practices are more amenable to change than others. Guidelines for cancer screening and the use of x-rays, blood tests, and pharmaceuticals have been implemented successfully. However, interventions to change practice for more complex clinical decisions have been less successful; for example, choosing between medical and surgical treatments.

Ensuring Quality Cancer Care concludes that a substantial number of Americans with cancer do not receive care known to be effective for their condition. However, the reasons for failure to deliver high-quality care have not been studied adequately, nor has there been much investigation of how appropriate standards vary from patient to patient.

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#bestpractice

National Comprehensive Cancer Network (NCCN)
www.cancernetwork.com/indexes/nccn.htm

The NCCN is a consortium of 17 leading cancer centers that has assembled expert panels to review evidence and develop guidelines on the treatment of numerous common cancers. Breast cancer practice guidelines and breast cancer screening practice guidelines are included on the NCCN Web site. All of the guidelines are presented in easy-to-use path or algorithm flow charts and article formats. The guidelines are evidence-based, and when no consensus is available, options are listed.

A publication, *Breast Cancer Treatment Guidelines for Patients*, produced collaboratively by NCCN and the American Cancer Society, (ACS) is also available on this Web site. The ACS translated the NCCN breast cancer treatment guidelines, originally developed for use by oncologists, into patient-friendly language and format. These guidelines are designed to provide patients and the general public the most current information about treatment options for breast cancer.

continued on page 5



What's Helpful on the Web? *continued from page 4*

American College of Surgeons (ACOS)
www.facs.org/

The ACOS Web site provides information and data pertinent to initiating a cancer registry program. It also contains a Cancer Practice Guidelines Index that provides a list of organizations affiliated with the ACOS Commission on Cancer (CoC) and the cancer practice guidelines the CoC submitted for review.

The ACOS CoC approval system for hospital cancer programs involves nearly 2,000 institutions. Its standards program provides clinical oversight and expertise for the CoC's standard-setting activities, and interfaces with others in the development, review, and dissemination of patient care guidelines.

American Society of Clinical Oncologists (ASCO)
www.asco.org

The ASCO practice guidelines are systematically developed statements designed to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances. Three publications: *Recommended Breast Cancer Surveillance Guidelines*, *A Patient's Guide: Follow-Up Care for Breast Cancer*, and *Cancer Pain Assessment and Treatment Curriculum Guidelines* are included on the ASCO Web site. Guidelines are evidence-based, with consensus demanded before approval.

The *Patient's Guide* is a booklet developed for breast cancer patients that explains what happens when breast cancer treatment is concluded. The booklet, available as a free download, provides ASCO's recommendations for tests that should be conducted as part of medical care following treatment for breast cancer.

National Guideline Clearinghouse™ (NGC)
www.guideline.gov/body_home_nf.asp?view=home

The NGC is a public resource for evidence-based clinical practice guidelines. NGC is sponsored by the Agency for Healthcare Research and Quality (formerly the Agency for Health Care Policy and Research) in partnership with the American Medical Association and the American Association of Health Plans. The site contains more than 50 breast cancer related guidelines, and is designed to provide health care providers and integrated delivery systems an accessible mechanism for obtaining objective, detailed

information on clinical practice guidelines and to further their dissemination, implementation, and use.

News

FROM THE BCDP SITES

The Breast Cancer Demonstration Project welcomes **New York Hospital Medical Center of Queens** to the Project.

E.F. Thompson Hospital's new Sands Cancer Center opened on April 17. The Center, which is a collaborative project of Thompson Health and Strong Memorial Hospital, will include integrative and complementary therapies. A coordinator for the Center was recently hired. EF Thompson Hospital also recently received grant funding from the Komen International Breast Cancer Foundation for breast health education materials, and a breast health fair and open house.

Sound Shore Medical Center's Nurse Coordinator recently completed a training program to become a Certified MammaCare specialist. MammaCare is a scientifically validated system for teaching and performing self-breast examinations. Certified Specialists are qualified to teach the technique to patients as well as other health care professionals in the field. For more information call (800) MAMCARE or go to www.mammacare.com.

North General Hospital has added a second Patient Navigator to assist patients with positive cancer findings. The hospital has also added a second Breast Cancer Screening Clinic. Effective April 1, 2000, North General is a subcontractor to the Breast Examination Center of Harlem as a provider for patients enrolled in the New York State Department of Health Breast Health Partnership.

continued on page 6

News from the BCDP Sites *continued from page 5*

This status will allow the hospital to provide follow-up to women with positive findings identified at the Breast Examination Center, as well as screening and intake of eligible women at North General. In addition, the Harlem Palliative Care Network, an initiative that includes North General, the Visiting Nurse Service of New York, and the Memorial Sloan-Kettering Cancer Center, was awarded a \$350,000 grant by the United Hospital Fund. The grant project will address cultural and resource barriers to palliative care in African-American and Latino communities and design appropriate strategies to overcome them.

New York Community Hospital has hired Pam Lemoux as a Patient Navigator. Pam has previously worked as a mammography technologist. Eileen Bartha, Vice President of Professional Services, reports that Pam will initially focus on developing her role and organizing a strong outreach program specifically designed to meet the needs of their multi-cultural community.

Long Island College Hospital, (LICH) has hired Shirley Burns, LPN, as a Breast Health Navigator. Shirley has worked in the LICH system for many years, and was most recently in charge of the Breast Center. She brings a vast array of knowledge to the navigator role. In preparation for this new position, Shirley oriented at Harlem Hospital Center, the American Cancer Society, and various Brooklyn Agencies.

Carole Facciponti, Administrator of the Othmer Cancer Center, reports that the Breast Health Navigator position has been extremely well received by the hospital and the

patients. Shirley continues in her position in the Breast Center on a limited basis and has been extremely effective in helping to break down barriers to screening. She has been particularly successful in assuring patients follow-up and return for subsequent exams.

New York Hospital Medical Center of Queens joined the BCDP at the beginning of March. Simon Fink, MD, Director of Surgical Oncology and Joan Scagliola, Resource & Information Coordinator in the Breast Cancer Center are representing the hospital on the Advisory Board.

New BCDP Director Starts at HANYS

Sandra Cassese, RN, BSN, has joined HANYS as the new Director of the Breast Cancer Demonstration Project. Sandra has extensive experience developing and managing breast cancer programs. She comes to us from Keller Army Hospital, West Point, New York, where she managed a Department of Defense contract to coordinate and improve breast health services for the hospital's patient population. Sandra can be reached at (518) 431-7661 or scassese@hanys.org.

HANYS' Offices are Moving

HANYS is relocating to Rensselaer, New York. The office will be closing at 5:00 p.m. on Thursday, May 4, 2000, and will reopen on Tuesday May 9, 2000 at 8:00 a.m. Effective May 9, 2000 our new address will be One Empire Drive, Rensselaer, New York 12144; all phone numbers will remain the same.

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