

LONG ISLAND COLLEGE HOSPITAL

Breast Health Navigator Program

“Breast cancer is a complex disease causing disruption in the physical, psychological, social, and spiritual aspects of caring. It is the role of the breast health navigator to pave the way for these women to access the necessary information from the professional and supportive staff that will make the journey less fearful and more understandable.”

– **Allan Gibofsky, M.D.**, President and Chief Executive Officer, Long Island College Hospital (LICH), Brooklyn, New York

In early 2000, LICH began the Breast Health Navigator Program at its Othmer Cancer Center. LICH serves a very diverse population in the Brooklyn Heights/Cobble Hill sections of Brooklyn comprised of ethnic and religious groups including African-Americans, Latinos, and persons of Indian, Italian, Jewish Orthodox, Russian Orthodox, West Indian, Haitian, and Arabic descent. Ninety-three percent of LICH's patients live in Brooklyn and 75% live within its primary service area, including the neighborhoods of Brooklyn Heights, Park Slope, Bedford-Stuyvesant, Crown Heights, Flatbush, Greenpoint, and Williamsburg. The LICH patient population is 45% African American; 28% Hispanic; and 27% Caucasian.

HANYS
Breast Cancer
Demonstration
Project™



Best Practices Strategy Guide

HANYS

HEALTHCARE ASSOCIATION OF NEW YORK STATE

WHAT IS A PATIENT NAVIGATOR?

A Patient Navigator is a person who serves as a proactive patient representative to help patients "navigate" the complex health care system. The navigator:

- *builds awareness in the patient of all available services, helps clarify choices, and ensures unrestricted access to all services;*
- *bridges gaps to care by ensuring that follow-up efforts are made so patients do not "fall through the cracks".*

Based on a review of women who obtain health care services at the LICH clinics, the LICH staff identified a need for additional support in the area of breast health and breast cancer. As one of the ten health care sites participating in the HANYS BCDP™ program, LICH health care professionals had access to information on a wide range of programs that provide services and assistance to patients with breast cancer. The program that seemed to best meet the needs of the women served by LICH was the Patient Navigator Program developed at Harlem Hospital.

A Patient Navigator is a person who serves as a proactive patient representative to help patients "navigate" the complex health care system. The navigator is a type of case manager who works congruently with the social worker, medical providers, financial clearance, and community social services to deliver treatment and follow-up services from the point of abnormal findings to follow-up. In other words, the navigator makes sure the patient is aware of and can access available services, and ensures that follow-up efforts are made so patients do not "fall through the cracks."

The first Patient Navigator program was piloted at Harlem Hospital through a grant funded by the American Cancer Society. This program forms the nucleus of the Hospital's Cancer Control Center, which was established to reduce the disproportionately high incidence of cancer in the Harlem community. The Harlem program:

- explored barriers to care encountered by patients;
- implemented and expanded the Patient Navigator's assistance to all patients once the barriers had been identified and resolved;
- developed a personal relationship and helped the patient obtain information so that she or he could understand the disease process and make an informed decision as to treatment;
- created a computer tracking system.

After keenly observing the Patient Navigator Program at Harlem Hospital, LICH designed its own model of patient navigation and called it the Breast Health Navigation (BHN) Program. Although based on the Harlem Hospital program, the BHN Program was tailored to meet the needs of LICH and the communities it serves. For example, the LICH program:

- incorporated a component on data collection so that outcomes and costs savings could be measured and evaluated,
- added a problem-solving or algorithm process, and
- expanded the role of the breast health navigators to enable them to track the patient throughout the breast

cancer trajectory (from screening through diagnosis, surgery, adjuvant therapy, and recovery).

The goal of LICH's BHN Program is to help women obtain recommended breast cancer screening services, diagnostics, and treatment and “navigate” through the clinical and supportive services. Through this navigation program, LICH is seeking to meet the physical and psychosocial needs of the women it serves. LICH BHN Program objectives include:

- identifying cultural and institutional factors (medical and non-medical) that act as barriers to service;
- linking women with institutional, community, and national breast cancer screening and early detection services, programs, and resources; and
- targeting breast health education to include community organizations that act as a gathering place for low-income and/or women who underutilize recommended breast cancer screening and early detection services.

“No patient should go through the cancer diagnosis alone,” said Carole Facciponti, Administrator of the Othmer Cancer Center. “It is our responsibility to ensure that all patients and their family members have access to the necessary supportive services. While LICH continues to ensure that these resources are available for all of our patients with a cancer diagnosis, *it is the Breast Health Navigator who ensures that these individuals are aware of the services and can access them.*”

During the first six months of the BHN Program, LICH identified the barriers to care and examined existing processes. Findings include:

- Staff were unable to schedule patients for their mammography appointments at the time of their breast, medical, or obstetrics/gynecology visits because the telephone lines were busy and the mammography department did not operate during the duration of clinic hours. Thus, patients were instructed to call the mammography department and often delayed calling or did not call at all.
- System procedures delayed mammography results in reaching the referring physicians and patients.
- The BHN program identified barriers that have impeded access to scheduled mammogram appointments. Two key reasons were identified: a) new patients were falling through the cracks because their appointments were short of the one full-year requirement for a screening mammogram and, b) a number of women did not feel the appointment was a priority.

QUALIFICATIONS FOR A PATIENT NAVIGATOR

Navigators need

- *excellent oral & written communication skills, interpersonal skills, organizational skills, listening & observation skills;*
- *flexibility, persistence, patience and the ability to work with all socio-economic levels;*
- *problem solving ability and a good knowledge of community resources;*
- *public speaking ability to educate providers and patients about navigation services.*

A member of the community with a history of working with local groups, collaborations, and advocacy outreach programs can be an ideal candidate.

SELECTED LICH BHN SOLUTIONS TO CARE BARRIERS, FOR USE BY THE PATIENT NAVIGATOR

- *Reserved time slots in radiology*
- *Patient appointment reminder calls*
- *In-service programs to educate staff about insurance regulations for screening mammographies*
- *Report tracking*
- *Using algorithms derived by the system for overcoming patient barriers to care such as child care, life-related issues, language barriers and cultural and socioeconomic fears*
- *Ongoing information and education for the health care team*

- Child care, other life-related issues, language barriers, and cultural and socioeconomic fears inhibited some women from accessing care or following up with services.
- There was not consistency in physician recommendations for the support services needed for women in the recovery phase after surgery.

Solutions

After several meetings with the interdisciplinary team, a new system for scheduling was implemented. The radiology department now reserves specific time slots for patients and provides a listing of those time slots to the breast clinic, obstetric/gynecology clinic, and medical clinics. This ensures more efficient scheduling and is a better way to identify clinic patients. The breast health navigator has a list of all patients scheduled and can call to remind patients about their appointments. The navigator is also aware in a more timely fashion if patients miss their appointments. The breast health navigator, using the appointment list, requests a mammography report and delivers it to the clinic on the day of the visit if it has not already been placed in the patient's chart. Before these changes, the turnaround time for the report being placed in the chart and available to the physician at the time of patient follow-up was up to ten days.

Algorithms were developed to address barriers such as childcare, other life-related issues, language barriers, and cultural and socioeconomic fears.

These algorithms provide a resource guide for the breast health navigator to use to ensure that all available resources are being accessed to address these barriers. In addition, the BHN Program is a way to identify new approaches that address barriers unique to the LICH population.

Two activities are underway to address missed scheduled appointments for mammograms. The first is in-service programs conducted by the breast health navigator to educate staff about insurance regulations for screening mammographies. The second is a change in standard operating procedure in the mammography suite—the receptionist is now calling all women scheduled for a screening mammogram within 24 to 48 hours to remind them of their appointments. If there are issues that preclude them from keeping their appointment, the breast health navigator will be notified and will use the appropriate algorithms.

LICH is hosting workshops for the health care team to examine patient fear and other common issues to develop a more consistent approach during this phase of care. In addition, information sessions with surgeons are scheduled to re-examine the objectives of institutional and

community resources, such as rehabilitation programs and the American Cancer Society's "Reach For Recovery" program, so that unmet patient needs can be identified and new programs for the care of women with breast cancer can be evaluated.

Outcomes to Date

The outcome data show the success of the LICH BHN Program. Achievements include:

- Ninety-nine percent of all clinic patients now have follow-up appointments scheduled before leaving the hospital. Before the BHN Program was implemented, only 25% of patients had follow-up visits scheduled.
- Patients are using more institutional and community resources. For example, the breast cancer support group has experienced a 20% increase in attendance of clinic patients who are referred by the breast health navigator.
- The improved tracking component of the BHN Program has enabled LICH to know the exact number of women who delay screening because of missed scheduled mammograms. In addition, the reasons for these missed appointments have been identified and are being addressed (as noted in an earlier section of this document).

Whether it is introducing patients to other cancer survivors or finding babysitting services, the LICH BHN Program is making the journey easier for patients and their families.

Based on individual comments, patients appear to be more satisfied with the care they received. Satisfaction survey instruments are being examined for use by women who are assisted by the breast health navigator. Recently, the LICH Department of Radiology conducted an outpatient survey in which the majority of respondents stated that their experience was very pleasant or satisfactory.

Cost savings from breast health navigator intervention are also being tracked. For example, a patient's length of stay (LOS) is decreased by one day because the breast health navigator moves rehabilitation appointments back a day when a physician order is written as "patient discharged home after Rehab consult." In the first phase of tracking this component of the program (October-December 2000), the breast health navigator found that only 6% of patients were referred for physical therapy and that there was a one-day extension in LOS because of the referral being written after transfer to a unit. Now, because of meetings with the surgical unit, the referral is incorporated into post-operative orders. Rehabilitation now responds immediately, and the data for

LICH BHN SELECTED OUTCOMES TO DATE

- *99% of all clinic patients are scheduled for their follow-up appointment*
- *20% increased attendance at the breast cancer support group*
- *Increased patient satisfaction*
- *Improved length of stay due to decreased delays in obtaining rehabilitation consults*

Some LICH BHN Examples:**WHATEVER IT TAKES TO HELP. . . .**

In December 1997, a 47-year-old African American woman came to the LICH obstetrics and gynecology clinic for an annual physical and was referred to the breast clinic because of suspicious mammography results. In 1998, she came to the LICH breast clinic to begin the process for a stereotactic biopsy. Over the next three years, until August 2000, this woman scheduled and cancelled numerous appointments for screenings and treatments, including the stereotactic biopsy, an ultrasound, and surgery. Throughout this three-year journey, LICH staff and the breast health navigator reached out to this woman and her family and worked to help address her various issues so that she would agree to access the care she so desperately needed.

The first issue she raised was that she needed a babysitter for her children (ages 5, 9, and 10). LICH staff and the BHN found a babysitter for her. Her second major stumbling block was that she was afraid. LICH staff and the BHN handled this by providing her the names and numbers of cancer survivors, who she was able to talk to. Finally these efforts paid off and in May 2000, the woman returned to the breast clinic ready for treatment. In August 2000, after three years of persuasion, support, and caring, she finally started with oncology.

"Last time I saw her, she was doing well and she told me that she was feeling good," said Shirley Burns the Breast Health Navigator.

the first quarter of 2001 revealed that 28% of patients were referred for physical therapy, resulting in no extended LOS and thus no delay in obtaining rehabilitation consults.

Keys to Success

"We are seeing unbelievable changes in this institution based on the data we have gathered and examined," said Fran Cartwright Al-Carese, R.N., Ph.D., Clinical Director of the Othmer Cancer Center. "Because of the cooperative collaboration of our interdisciplinary team, we are identifying significant issues that need to be addressed and implementing many changes. One of our challenges and frustrations continues to be reaching women and getting them here for screening **before** treatment is needed and getting them to come and continue treatment when they have late stage disease."

"I believe the collaborative efforts between the breast health navigator and the radiology and mammography staff have been essential for the project's success. Our combined efforts are aimed at ensuring that the patients who need our services the most do not fall through the cracks. We accomplish this through good communication among ourselves, resolving problems quickly, patient phone calls, recall letters, and patient education through community outreach programs."

Michele Schiraldi, A.A., R.T.(R)(M),
Coordinator of Mammography, LICH

"The first year of this program has helped show us areas where we can better share resources, improve patient care, and enhance the quality of services," said Ms. Cartwright Al-Carese. "We have all worked hard and worked together to build community trust for our medical institution."

After one and a half years of experience with its BHN Program, the LICH staff identify the following as key factors for its success:

- Data drives the change. The data gathered and tracked through the program have helped identify resources that were lacking so that changes could be made. Before the program, LICH staff sensed that cases were "falling through the cracks" but did not have the resources to address this.
- Selecting the right person to be the navigator is essential. At LICH, the BHN selected was Shirley Burns, a licensed practical nurse who has been with LICH for 34 years, has been a member of the community all of her life, and has a history of patient advocacy. For nearly 20 years she had been involved in the breast clinic and had a reputation among staff and patients alike as a "do-er."

- Surgeons and radiologists are critical to the program's success. Because the BHN Program relies on interdisciplinary teamwork, it is essential that key players such as surgeons and radiologists be involved in the design and continuing implementation.
- Networking with others in the area of breast health and breast cancer provides unforeseen opportunities. It was through the HANYS BCDP™ and participation on the Advisory Board that LICH was aware of the Harlem Hospital Navigation Program and its application for LICH.
- Emotional support and referrals are critical for women after surgery. As national research shows, these support services not only help comfort, they help extend individuals' life spans.
- All women can use the assistance of the breast health navigator. The initial target population of the LICH program was vulnerable, low-income women, with the majority of them using the hospital clinics for care. However, since its inception, the BHN Program services have been expanded for all women.
- It is important to think ahead and build on the program. Just as patient and community needs change, so too should the breast health navigator program.

Next Steps for the LICH Program

The LICH Breast Health Navigator has achieved success in helping women obtain breast health screening and diagnostics and in providing support to women diagnosed with breast cancer. The breast health team is now going beyond just those who come to the hospital and its clinic and are beginning to reach out to the community. First, they are focusing on working with the families of those already in the LICH network of care and encouraging family members to be screened for breast cancer. In addition, they are working with community organizations and conducting presentations to educate women about the importance of breast health screenings and how to access the diagnostic services and treatment that may be required. One community venue is local churches. As one LICH staff member pointed out, "We are going where the ladies gather, and the ladies gather at church."

Some LICH BHN On-site Examples (Contd.):

OVERCOMING LANGUAGE AND FINANCIAL BARRIERS

In October 1999, a 34-year old woman came to the LICH emergency department with multiple masses in her breast and a serious infection. However, she was not a U.S. citizen and, therefore, not eligible for Medicaid. She could not speak English. She was referred to the LICH breast clinic where she received medication for her infection. Within a month, she returned to the clinic in a great deal of pain and LICH provided her with more medication.

In early 2000, this young woman came back to the breast clinic with another massive infection and the LICH staff began a series of injections every two weeks. By February, it was clear that she would need a partial mastectomy.

To address the financial issues, the breast health navigator worked with this family and helped them apply for emergency approval for Medicaid, enabling this young Hispanic woman to afford the surgery she so desperately required. The Breast Health Navigator provided the emotional support and identified the resources this family needed. In April, the patient underwent surgery at LICH.

"She still comes back to see me and although she can't speak English, she communicates with a big hug," said Ms. Shirley Burns, the Breast Health Navigator. "I'm so glad we were able to help her."

BENEFITS OF PATIENT NAVIGATOR PROGRAMS

Patient navigation programs have numerous benefits for patients and communities as well as for the hospital conducting the program. Some of the benefits include:

- *improved coordination of high quality, compassionate care,*
- *enhanced access to services for vulnerable populations and enhanced quality of care for all women,*
- *removal of barriers to care,*
- *more efficient delivery of care,*
- *improved sharing of resources both within the hospital and with community organizations,*
- *enhanced outcomes,*
- *documented cost savings for intervention through tracking costs,*
- *enhanced relationships with the community, and*
- *increased patient satisfaction.*

LICH is also seeking to expand the diversity of the population it serves. While African American women were one of the first populations in the community targeted by the BHN Program, the breast health team envisions engaging in activities for other ethnic and cultural groups. They view HANYS as an important resource in this endeavor. According to Fran Cartwright Al-Carese, “HANYS is an unbelievable resource for addressing the needs of different ethnicities and cultural groups. We feel very fortunate to be part of HANYS Breast Cancer Demonstration Project™ and Advisory Board and have the opportunity to learn about the multiple resources available and meet others who share of mission of caring and supporting women in the area of breast health.”

About Patient Navigation Programs and Their Benefits

Harold P. Freeman, M.D., who at the time was President of the American Cancer Society, originally proposed the concept for Patient Navigator programs in 1989. This program was a direct outgrowth of the results of 1989 American Cancer Society national hearings on cancer and the poor. The specific findings that led to the Patient Navigator program included:

- poor people endure greater pain and suffering from cancer than other Americans;
- poor people face substantial obstacles in obtaining and using health insurance and often do not seek needed care if they cannot pay for it;
- poor people and their families must make extraordinary personal sacrifices to obtain and pay for health care; and
- fatalism about cancer prevails among the poor and prevents them from gaining quality health care.

A Patient Navigator was initially defined as a “social servant,” a proactive patient representative, distinct from the hospital social worker, who focuses on the concrete needs of the cancer patient and reflects a special concern for ensuring prompt follow-up. This definition formed the foundation of virtually all navigation programs. The role has been broadened somewhat to include elements of psychosocial and emotional support.

Patient navigation programs have numerous benefits for patients and communities as well as for the hospital conducting the program. They increase the coordination of high quality, compassionate care and increase access to services for vulnerable populations. They have the potential to removal of barriers to care and make the care delivered more efficient. In addition, they improve sharing of resources both

within the hospital and between the hospital and community organizations. As has been documented by the LICH BHN program they result in better outcomes and promote cost savings for the intervention through tracking costs. They ultimately lead to enhanced relationships with the community, and increased patient satisfaction.

Patient navigation programs are being adapted by other hospitals throughout New York State and tailored to meet the needs of individual communities.

Resources and Tools for the Breast Health Navigator

A variety of resources and tools are available to help breast health navigators when assisting breast cancer patients. Below are some examples:

A Helping Hand: The Resource Guide for People with Cancer.

Cancer Care, Inc. 275 Seventh Avenue, New York, NY 10001

It is available free in bound version by calling (800) 813-4673 or online at www.cancercare.org/hhrd/hhrd.htm.

The Helping Hand Resource Guide is a nationwide directory of free services and resources for people with cancer. The guide is designed for health care professionals and for cancer patients and their families. The guide has listings of national, regional, state, and local organizations, and national cancer centers, retailers, and other groups and agencies that help people with cancer. *The Helping Hand Resource Guide* contains information about services including advocacy, financial assistance, home care, hospice care, housing and lodging, medication manufacturers' indigent drug programs, minority health services, patient-to-patient support, state pharmaceutical assistance programs, survivor concerns, and transportation services. All listings are indexed alphabetically, by service, cancer site, e-mail, and "800" number. Whether you are looking for general information on cancer, or specific services, this guide is designed to answer your questions or direct you to someone who can.

Case Management Resource Guide, Volume 1: Eastern U.S.

Center for Healthcare Information, PO Box 16067, Irvine, CA 92623

Available in bound version for \$49 by calling (800) 627-2244 or free online at www.cmrg.com/guide.htm.

The Case Management Resource Guide lists health organization, self-help groups, government agencies, and clearinghouses that provide information or support resources for patients and their families. It is designed for use by case managers, discharge planners, and social workers, among others. Cancer management resources include: disease management programs and vendors, information and support

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Innovative Approaches to Patient Care Case Management Related Journals

Lippincott's Nursing Center.com

Available free online at www.nursing-center.com/journals

The Cancer Survival Tool-Box™ National Coalition for Cancer Survivorship (NCCS)

1010 Wayne Avenue, Suite 505 Silver Spring, MD 20910-5600

Available free online at www.cansearch.org/programs/tool-box.htm. Available free in audio cassettes with booklet by calling (877) 866-5748.

MEDLINEplus Health Information Breast Cancer Page

National Library of Medicine at the National Institutes of Health

Available free online at www.nlm.nih.gov/medlineplus/breast-cancer.html. Available in English and Spanish.

resources, manufacturers of home care and assistive technology products, and relevant Web sites. Topics include diseases, health conditions, and health issues. Health-related state agencies that are listed provide information or financial support, and can refer you to other local services. Many of the national organizations listed can also refer you to their local chapters.

Innovative Approaches to Patient Care Case Management Related Journals

Lippincott's NursingCenter.com

Available free online at www.nursingcenter.com/journals

NursingCenter.com links to online journals that may be helpful when researching and developing case management programs. Many articles from the journals can be read online and printed free; others are available for a modest fee. Full-text journal articles are fully searchable; issues are available from January 1996 forward. Journals listed include Nursing Case Management, Outcomes Management for Nursing Practice, Cancer Nursing, Nursing Research, Computers in Nursing, and more.

The Cancer Survival Tool-Box™ National Coalition for Cancer Survivorship (NCCS)

1010 Wayne Avenue, Suite 505 Silver Spring, MD 20910-5600

Available free online at www.cansearch.org/programs/toolbox.htm. Available free in audiocassettes with booklet by calling (877) 866-5748.

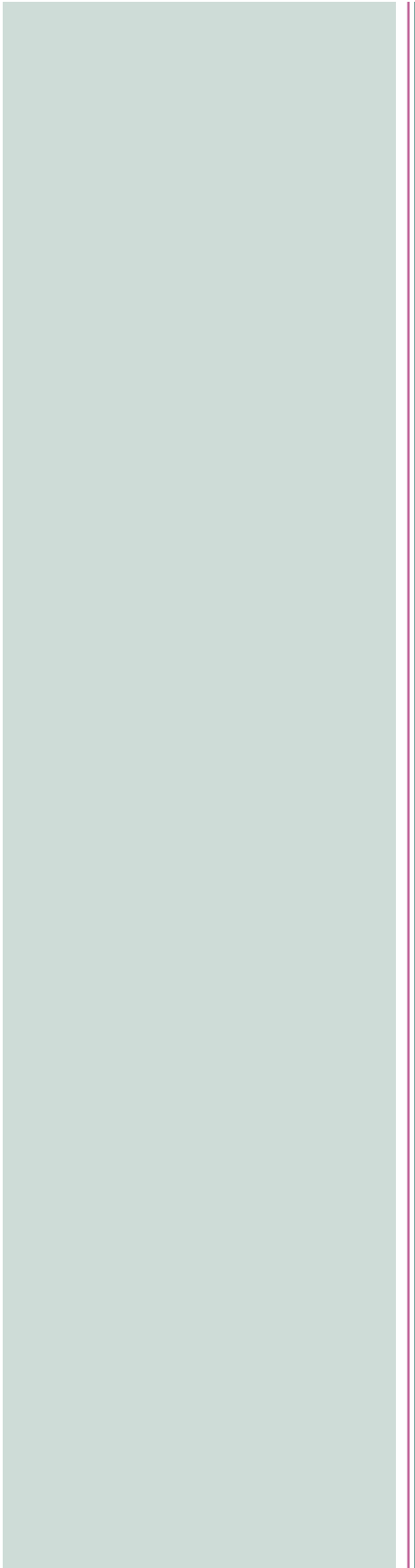
The Cancer Survival Tool-Box™, a self-learning audio program, is designed to help individuals with cancer learn about practical topics and skills that can help them meet the challenges of their cancer diagnosis and treatment. The toolbox includes six self-learning audio programs: communicating, finding information, making decisions, solving problems, negotiating, and standing up for your rights. A new tape, "Finding Ways to Pay for Care," has been added to the box, and is designed to address the specific issues faced by individuals who have either inadequate or no health insurance. The program is designed to assist anyone, at any stage of illness, who is facing hard decisions and changes in life because of cancer. Family members and caregivers can also use the toolbox on behalf of a child or anyone else with cancer. Survivors, social workers, and nurses, representing a unique collaboration of the National Coalition for Cancer Survivorship, the Association of Oncology Social Work, and the Oncology Nursing Society designed the Cancer Survival Tool-Box™.

MEDLINEplus Health Information Breast Cancer Page

National Library of Medicine at the National Institutes of Health

Available free online at www.nlm.nih.gov/medlineplus/breastcancer.html. Available in English and Spanish.

MEDLINEplus, a Web-based program designed to help consumers easily access health information on the Internet, has been implemented by the National Library of Medicine at the National Institutes of Health (NIH). The MEDLINEplus' breast cancer page is intended for both consumers and health professionals with medical questions about breast cancer. This service provides access to extensive information about breast cancer, and also has links to consumer health information from NIH, clearinghouses, dictionaries, lists of hospitals and physicians, health information in Spanish and other languages, and clinical trials.



HEALTHCARE ASSOCIATION OF NEW YORK STATE
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