

The Johns Hopkins Avon Foundation Breast Center

by Lillie Shockney, RN, BS, MAS



Lillie Shockney, RN, BS, MAS, with Johns Hopkins Avon Foundation co-directors, Theodore Tsangaris, MD (standing) and Nagi Khouri, MD.

When the Johns Hopkins Breast program was established two decades ago, breast cancer was a disease on the rise. It was apparent that a dedicated program addressing the needs of women with breast cancer would be of paramount importance to a successful women's health program. The Breast Center's philosophy is that we are here for the primary purpose of treating breast cancer patients. Our goals are to:

- Limit the trauma of diagnosis and treatment of this very serious illness.
- Render our services with compassion and professional skill.
- Allow nothing to interfere with what is in our patient's best interest.
- Be our patient's advocate in interaction with the health-care system.

Our Patients

The Breast Center does no formal advertising. More than 50 percent of our newly diagnosed breast cancer patients

come to us by having accessed our website (www.hopkins-breastcenter.org) and/or having received help after posting a question to our administrative director. We see and treat more than 750 newly diagnosed breast cancer patients a year and follow thousands more. Eighty percent of our mammograms are diagnostic and 20 percent are for screening down-town at our Center. An overview of the types of patients seen at the Hopkins Breast Center includes women who:

- Discover a breast lump
- Have an abnormal mammogram or biopsy
- Have recently been diagnosed with breast cancer
- Want a pathology (second opinion) consultation
- Need breast cancer treatment
- Need breast cancer recovery advice or rehabilitation
- Are considering breast reconstruction
- Are concerned about their breast cancer risk
- Want to learn about breast self examination
- Want genetic counseling for themselves or a family member
- Need lymphedema prevention and/or management

- Want a breast specialist to routinely perform their clinical breast exams
- Seek support services from Johns Hopkins breast cancer survivor volunteers
- Seek possible participation in National Cancer Institute-sponsored clinical trials.

Turn to page 41 for a look at a sample patient encounter.

Our Services

As part of the Johns Hopkins Hospital, the Breast Center stands at the forefront of breast cancer research and treatment. The Center's state-of-the-art technologies and highly skilled medical professionals are internationally recognized. Patients who visit the Breast Center have access to the most advanced tests and therapies available.

Patient consultations may involve one or more of the following services.

Specialized diagnostic evaluation and testing. These services include radiological evaluation (e.g., mammography, ultrasound, and newer imaging techniques) and biopsies (e.g., fine-needle, core-needle and stereotactic biopsy, and surgical biopsy).

Consultation and treatment with breast cancer specialists. Our providers have focused expertise in breast cancer surgery, breast reconstructive surgery, and adjuvant treatments. Our program offers lumpectomy and mastectomy reconstructive surgery, including DIEP flap or S-GAP reconstruction; drug therapy, including hormonal therapy, chemotherapy, or targeted therapy; and radiation therapy, including computer-assisted treatment planning, partial breast radiation, and accelerated radiation.

Second opinions for newly diagnosed and recurrent breast cancer patients. Our providers perform consultations to review surgical and radiation oncology treatment recommendations given to the patient from other providers. We offer limited consultations for medical oncology evaluations for who live outside our regional area. Our providers also perform consultative reviews mammography films or pathology slides.

Access to NCI-sponsored clinical trials. We offer patients access to a full-range of clinical trials, including: radiology and breast imaging clinical trials, surgical and plastic surgery clinical trials, hormone therapy trials, chemotherapy trials, and radiation therapy trials.

Psychological counseling and support. Providers are available for individual and family psychotherapy and counseling.

Our program offers support group programs for breast cancer patients, breast cancer survivors, and their family members. For example, our volunteer program, *Survivors Helping Survivors*, offers newly diagnosed breast

cancer patients the opportunity to meet with an oncology nurse who is a breast cancer survivor. Patients can also be "matched" to a specially trained survivor volunteer. Patients are matched based on age, stage of disease, and anticipated treatment plan. In addition, 10 survivor volunteers take turns coming onsite to hold the hands of women having breast biopsies or other invasive procedures such as wire localizations. Patients, faculty, and technicians value this service, which helps reduce anxiety and provides a vision of hope to worried patients.

We also offer semiannual survivor retreats. These special programs are designed to help women re-engage in their lives emotionally healthier as they transition from being patients to feeling like survivors.

Physical and occupational therapy. Our services include: pre-operative rehabilitation consultation and lymphedema prevention; lymphedema management; and post-operative therapy for arm strengthening.

Comprehensive patient education. As part of our patient-centered model of care, our program has developed a variety of educational offerings, such as a preoperative educational program for patients and their caregivers at home; professional guidance on hormone replacement therapy; educational seminars on topics of interest to women with breast cancer or a history of the disease; and training and education on breast health.

As part of our *Community Ambassador Program*, breast survivor volunteers receive training through the American Cancer Society's certification program for breast health educators in order to conduct education programs in local communities. These well-trained volunteers also staff health fair booths and provide educational information for other venues such as churches or PTAs.

Preventive services. Our breast cancer patients benefit from a wide range of preventive services including: an assessment of breast cancer risk based on family history and other factors; instruction in breast self exam; recommendations for mammography and other types of screening; and risk-reduction techniques achieved through lifestyle changes.

Our Staff

The Breast Center's structure is highly specialized and staffed with faculty, nurses, and technicians who offer expertise in breast health, breast disease, and breast cancer. Center staff includes four surgical oncologists, six medical oncologists, three radiation oncologists, three plastic surgeons, three pathologists, two genetics experts, two surgical oncology nurse practitioners, three medical oncology research nurses, two medical oncology nurse practitioners, one radiation oncology nurse, two radiologists, seven breast imaging technologists, a biopsy coordinator, two patient advocates who are oncology nurses and breast cancer survi-

vors, and more than 30 Hopkins breast cancer survivor volunteers. In addition, oncology social workers, case workers, outreach nurses in the community, and epidemiologists round out our breast care team.

A key staff member is our new patient appointment scheduler who is responsible for scheduling surgical oncology, plastic surgery, high risk, and diagnostic evaluation patients for new appointments in the Center. Medical oncology and radiation oncology appointments are scheduled by the oncology referral office after the patient has had her initial consultation and a surgical treatment plan is known. Center staff also includes a dedicated OR scheduler to arrange and coordinate the surgery date, pre-op teaching appointments, pre-op testing appointments, and other needed tests/arrangements for the patient's surgery.

Our multidisciplinary Breast Cancer Tumor Board meets weekly and discusses cases of interest that are more complex than average cases and that require joint discussion and the participation of the entire team. Minutes are recorded from these meetings. We also conduct educational programs at every other tumor board meeting. These programs might include a new finding or treatment in clinical practice or an update related to research findings.

Our Organizational Structure

The Breast Center is led by a medical director and an administrative director. The medical director is a breast surgical oncologist and also serves as the chief of breast surgery at Hopkins. The administrative director is an oncology nurse and two-time breast cancer survivor with an MBA and expertise in performance improvement. The administrative director also chairs the National Consortium of Breast Centers' Quality Initiative, which has created and implemented a set of quality measures that look across the spectrum at quality of care for women diagnosed and treated with breast cancer. (For more information, visit www.breastcare.org.) The Division of Breast Imaging has its own medical director who oversees the diagnostic evaluations performed on patients with the majority of biopsies being performed by that discipline.

Our Center's Executive Committee includes representatives from each discipline. This committee meets every other week to:

- Discuss goals and objectives of the center
- Identify relevant issues that impact the operational management of the center
- Review new technology or treatment planning that may alter the current protocols or working relationships of the disciplines
- Maintain a pulse on what is happening in the center
- Plan our biannual regional breast cancer conference



The Johns Hopkins Breast Center was established in 1994 with the mission to provide optimal breast healthcare using a comprehensive multidisciplinary approach. The program's patient-focused, multidisciplinary breast care model provides innovative, integrated, high-quality, cost-effective breast care covering the full spectrum of clinical and support services—from screening and diagnosis to treatment and counseling.

- Address specific needs any discipline in need of leadership support.

The Center holds an annual retreat for all center staff. This day-long event is an opportunity to:

- Review programmatic and professional goals and objectives
- Receive feedback regarding any upcoming changes that will impact the breast center and its current operations
- Review patient satisfaction survey information. (Our patient survey tool and its results are available on our website at www.hopkinsbreastcenter.org.) Additionally, volunteers serve as objective "ears and eyes" to provide candid feedback on the care and services we are providing to patients.
- Discuss and develop strategic plans for the Center
- Identify opportunities for improvement and construct work groups for achieving those improvements
- Review service standards and clinical quality outcomes measures, as well as look at issues related to efficiency and effectiveness.

Our Outreach Efforts

Addressing the needs of the underserved is a challenge for any breast center. At Hopkins, we use special grant funds to assist us in providing case workers and nurses who reach out to the local east Baltimore community to educate and inspire women to come to Hopkins for mammograms and clinical breast exams. As a part of this outreach effort, our program provides transportation and one-on-one patient navigation. Screening mammograms are read in real-time to avoid having to do call backs for patients. This practice also allows for diagnostic evaluation, if warranted, to be performed during the same visit. For women who are diagnosed with breast cancer, we use

Sample Patient Encounter

STEP 1—Patient calls after a lump is felt when a breast self-exam is performed. An appointment for diagnostic evaluation is scheduled within 48 hours.

STEP 2—Patient is seen for diagnostic evaluation. If bi-rad 4 or 5, a biopsy is performed that same day. A survivor volunteer is present with the patient for support.

STEP 3—Patient is notified of the biopsy results within 48 hours. If results are positive, the patient is referred immediately to scheduling coordinator to make an appointment with a surgical oncologist.

STEP 4—Patient is seen 48 hours later by a breast surgical oncologist and oncology nurse/breast cancer survivor. At this appointment a surgical treatment plan is developed. A great deal of time is spent educating the patient and providing her with written information about breast cancer and the specifics of her anticipated treatment. She also is seen by a research nurse to determine if she qualifies for any innovative research protocols. Before the patient leaves the center, she is offered the opportunity to be matched to a survivor volunteer and is scheduled for her surgery date by the OR scheduling coordinator, who is based in the center. When her surgery date is confirmed, the oncology referral office is notified and arranges for a medical oncology consultation two weeks post-op and radiation oncology (if the patient had lumpectomy surgery) three weeks post-op.

STEP 5—Patients having mastectomy with reconstruction are also seen by a plastic surgeon to review their reconstruction options. Patients undergoing procedures that will involve drains are scheduled for pre-operative teaching classes provided one-on-one by a nurse practitioner in the breast center who works closely with the surgeons who will be operating on the patient. Anesthesia evaluation is also done at that time.

STEP 6—On the day of surgery, the patient is seen by an oncology nurse/breast cancer survivor for support. This visit is conducted pre-op and post-op. In the recovery room the patient is provided a comfort bag assembled by the survivor volunteer team. The patient is given instruc-

tions for home care (if ambulatory surgery performed) or admitted to the inpatient ward where she will receive these instructions upon discharge. She will also receive her post-op appointment, which usually is scheduled five to seven days after the surgery.

STEP 7—The nurse practitioner who works closely with the surgeon who performed the operation contacts the patient to answer any questions prior to her post-op visit. At the post-op visit, the pathology report is reviewed with the patient and patient is provided with a copy. At this visit, staff confirms that the patient has scheduled her medical oncology and radiation oncology appointments.

STEP 8—The patient continues to be seen by the nurse practitioner at specific intervals during the course of her adjuvant therapy, which is being provided by medical oncology and radiation oncology.

STEP 9—When the patient has completed all treatment, except hormonal therapy, she is mailed a patient satisfaction survey to complete and return, anonymously, to the administrative director.

STEP 10—Patients who are doing well several years after completion of treatment become candidates to be followed long-term by one of our nurse practitioners independently.

ADDITIONAL STEPS, IF NECESSARY—If at any time during treatment the patient manifests emotional concerns, she is referred to the cancer counseling center for psychotherapy. Her family is also offered this service.

Patients with a significant history of breast cancer will be referred to the Breast and Ovarian Surveillance Service (BOSS) program for genetic counseling and testing.

Patients experiencing lymphedema are referred to rehabilitation medicine therapists who are certified in lymphedema management.

Patients with other co-morbid conditions that have not been properly evaluated are referred to a specialist within Hopkins for assessment and treatment as appropriate.

state grant funds and funds from The Red Devils, a local charitable organization supporting Maryland families living with breast cancer, to support the expenses of their care. With these funds we are able to offer patients financial assistance for transportation, food, house cleaning, and childcare during treatment, as well as coverage of medicines if needed.

Trained volunteers assist with the Breast Center's annual fundraisers, as well with other organizations we support such as the Avon Foundation, the Komen Race for the Cure, the American Cancer Society, and The Red Dev-

ils. Breast Center volunteers also act as lobbyists and activists. Several of our volunteers have become National Breast Cancer Coalition Project Lead-trained and can provide invaluable assistance on issues that warrant governmental support and policy changes. 📞

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The Johns Hopkins Avon Foundation Breast Center Patient Bill of Rights

WE BELIEVE that each of us is the person best equipped to solve our patient's problems in our area of expertise, and that, working together, we can best improve the care for each patient. Under our philosophy of care, every patient has the right to directly participate in the decision-making about her care and treatment. Our responsibility is to empower patients with information and educate them so that they can be active participants in their breast health care teams. To this effect, our program developed a breast-cancer-specific patients' bill of rights:

PATIENTS who have been advised to see a surgeon due to an abnormal mammogram or breast lump should be seen as soon as feasibly possible by a physician who specializes in diagnostics for breast cancer diagnosis and treatment.

PATIENTS can expect to be evaluated by a multidisciplinary team of health care professionals dedicated to the diagnosis and treatment of women with breast cancer. This team should consist of several surgical oncologists, medical oncologists, radiation oncologists, radiologists, plastic surgeons, pathologists, nurses, social workers/counselors, genetics expert, and rehabilitation therapists, all of whom specialize in breast cancer treatment.

PATIENTS should expect to be cared for by physicians who are board certified by the medical profession in the treatment of breast cancer.

PATIENTS have the right to receive the best care and treatment possible. This is best provided by a hospital who meets the standards defined by the Approvals Program of the Commission on Cancer of the American college of Surgeons.

PATIENTS should have the right to directly participate in the decision making about their care and treatment. They should be treated as an equal partner of the health care team starting at the time of their first appointment for evaluation.

PATIENTS have the right to information about their diagnosis and treatment options. The education process should begin at the time of their first appointment for evaluation. Information should be provided verbally and in writing as a means of ensuring effective communication.

PATIENT'S family members should be encouraged to take part in supporting the patient, both physically and emotionally. Designated family members chosen by the patient should be encouraged to participate with the patient in educational sessions conducted by the health care staff with the patient.

PATIENTS should have the opportunity to participate in clinical trials related to breast cancer treatment and

should be provided information about these trials that they qualify for throughout their diagnosis and treatment phases.

PATIENTS should expect to be treated by doctors and nurses who can provide state of the art care. They should be given access to state of the art surgical care, medical oncology care, radiological care, and radiation oncology care, rehabilitations and nursing care. To accomplish this, the latest technology available must be accessed whenever appropriate and patients should feel assured that the most comprehensive and up to date treatment options will be utilized.

PATIENTS should expect to be medically and surgically managed with every effort to prevent or minimize side effects of breast cancer treatment.

PATIENTS should to be able to express their opinions openly, freely and be heard. If they have concerns about their care or wish to make recommendations to the staff for improving care or services, their opinion should be taken seriously.

PATIENTS have the right to talk with patients previously diagnosed and treated in the Breast Center to obtain answers to candid questions and to receive ongoing emotional support.

PATIENTS have the right to expect effective continuity of care, including timely communication between the Breast Center physicians and the patients' referring physicians and other health care providers.

PATIENTS can expect urgent care needs to be effectively addressed. Health care professionals are available 24 hours a day, 7 days a week to accomplish this.

PATIENTS can expect to have their emotional needs and that of their families personally and individually assessed and supported through interventions made by the physicians, nurses, social workers and counselors.

PATIENTS should expect to be offered on-going education programs about breast cancer treatments, survivorship issues, new discoveries and the latest in clinical management. These educational offerings should be provided on a continuous basis and patients in treatment as well as those who have completed treatment are encouraged to participate.

PATIENTS should expect to be offered resources to help with image recovery, targeted at improving and rebuilding self image and self esteem which may change as a result of breast cancer treatment. The goal is to restore the patients' health status, including their emotional well being.