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What Light Through Yonder Window Wreaks Circadian Rhythms and Breast Cancer

By Sharon Batt

It was the opening session of a workshop exploring the effect that artificial light has on breast cancer risk, and University of Connecticut epidemiologist Richard Stevens showed an aerial slide of the United States by night. Dots of white city lights twinkled against the blackness, coalescing into splotches in areas of high population density.

The pattern recalled maps showing the geographical distribution of breast cancer rates, with the high-incidence areas along the northeast coast, the Great Lakes' boundary, and in the coastal cities of California.¹ The image neatly captured the hypothesis that participants would consider for the next two days at the conference ("Circadian Disruption as Endocrine Disruption in Breast Cancer," sponsored by the National Action Plan on Breast Cancer): that artificial light at night is a type of pollution that contributes to breast cancer.

The hormone melatonin is produced at night and regulates circadian rhythms, our daily wake-sleep patterns. Give people melatonin supplements and they nod off. Artificially reverse light and dark, and melatonin production switches accordingly; so do sleep rhythms. As we age, calcium deposits accumulate in the pineal gland, which produces melatonin — and some researchers suspect that both melatonin levels and hours of sleep may be diminished as a result.

Melatonin has cancer-fighting properties. Seventy-five percent of cancer shows oxidated DNA damage. Melatonin rivals vitamin C in its ability to counteract the oxidating effects of estrogen and radiation.

The discovery that the pineal gland actually secretes something dates only to the 1970s, but this hormone of darkness is

ancient. Species at all evolutionary levels, from algae to moths to humans, secrete melatonin at night. Nature tripped these circadian switches until a century ago, when Thomas Edison invented electric light. We in the industrialized North can now choose from 15,000 sources of artificial light to shorten our long winter nights.



"If light were a drug, I'm not sure the Food and Drug Administration would approve it," Charles A. Czeisler quipped in the *Medical Tribune* last year. Even tiny slivers of light at night disrupt the melatonin levels of rats, promoting tumor growth. Removing the pineal gland in rats stimulates tumor growth, and melatonin inhibits the growth of estrogen-receptor-positive (ER+) breast cancer cells in vitro by 30 to 40 percent. This leads researchers to speculate that reducing our exposure to light at night might decrease rates, and that pharmacological use of melatonin may be effective in treating cancer.

Research Findings

Josephine Arendt, a professor at the Centre for Chronobiology in Surrey, England, became interested in melatonin after she was diagnosed with breast cancer 19 years ago. Her work illustrates the difficulty of testing hypotheses with real-world studies. Comparing blood serum melatonin levels of sighted individuals living in the United Kingdom with those of blind people and inhabitants of parts of Antarctica where the sun does not rise at all for three months, Arendt found no significant differences. Two studies of profoundly blind women have

CALENDAR

BCA EVENTS

September 28, 7 p.m. to 9 p.m., a reception at Catherine Jane, a clothing boutique at 1234 Ninth Avenue in San Francisco. A percentage of the store's October sales will be donated to BCA. Admission is free; refreshments will be served. For more information, call Robby Robinson at 650/342-5566 or e-mail RobbyLon@aol.com.

October 16, 7 p.m. to 10 p.m., "Strike Out Breast Cancer," an evening of bowling, food, and a silent auction to benefit BCA and others. Presidio Bowling Center, Presidio bldg. 93 (at the corner of Montgomery and Moraga), San Francisco. \$100. For more information, call 415/864-8523.

October 19, 6 p.m. to 8:30 p.m., "The First Look," a book launch celebration and mastectomy issues forum. At the Hang Gallery, 556 Sutter St., San Francisco. Free. Call the BCA office at 415/243-9301 for details.

OTHER EVENTS

September 26, 7 p.m., "Environmental Estrogens: Should We Be Concerned?" A presentation by Tufts University School of Medicine professor Ana Soto. Marin County Civic Center, 3501 Civic Center Drive, San Rafael, California. Free. For more information, call 415/256-9011.

From the Executive Director

Drug Dangers, Double Standards, and Echoes from the Past

By Barbara A. Brenner

As we approach another October that will inevitably be full of mammography hype and "look good, feel better" approaches to the breast cancer epidemic, I find myself thinking about recent events and common trends in breast cancer. My thoughts fall into three categories: bad news on Herceptin; double standards in cancer treatment; and the persistent messages of Breast Cancer Awareness Month. I think these things are related and that, taken together, they help explain the continuing importance of Breast Cancer Action's work.

Earlier this year, as reported in our last newsletter, there was a great deal of press attention to an advisory issued by Genentech, the manufacturer of the drug Herceptin. Fifteen of the 25,000 women who have been treated with the drug had died as a result of the treatment, and an additional 47 had experienced serious adverse reactions.

Press calls to BCA asked whether we thought the drug should be taken off the market. One e-mail I received suggested that Genentech should be put on trial as a mass murderer. And I was asked how we could continue to support the availability of Herceptin yet oppose the approval of tamoxifen for use in healthy women to reduce their risk of developing breast cancer.

Keeping in mind that Herceptin is approved for use in women who have metastatic disease — cancer that will almost inevitably kill them unless something else gets them first — the question about taking the drug off the market is misplaced, and the suggestion that Genentech is a corporate criminal for offering the drug in the first place is more so. We're not talking here about women whose cancer is in remission, who might receive Herceptin on an adjuvant basis (that use is currently in trial). We're talking about women whose cancer is active and has already spread, who are facing death in the relatively near term, and for some of whom Herceptin has the potential to prolong life. The world of risks and benefits looks very different for those women compared with that for women whose lives are not in immediate danger.

While every death from Herceptin is a tragedy, the fact is that more than 99 percent of the women treated with the drug have not had adverse reactions to the drug. There is no such thing as a drug that works with no risks, and Herceptin is the first drug in years that provides the possibility of extending the lives of some women with metastatic disease without the brutal side effects commonly associated with cytotoxic chemotherapy agents.

The deaths and other harm from the drug itself require us to be diligent about informing women about the risks and making sure that doctors monitor patients both for the side effects and for the conditions that increase the risk of incurring them. And, as with all new therapies, ongoing monitoring of their effects is imperative so that new information about benefits and risks is provided to patients and doctors as soon as it becomes available.

These views are easily reconciled with BCA's opposition to the marketing of tamoxifen for breast cancer risk reduction in healthy women: Consider the population that is

From the trenches of the war on cancer, the world looks decidedly less rosy.

receiving the drug. When we are talking about medical interventions for healthy women, the standards for making drugs available should be decidedly different from what they should be when the issue is treatment for women who have breast cancer. The balance of risks and benefits looks far different when the woman receiving a potentially dangerous drug (tamoxifen is a known carcinogen) is healthy as opposed to when she is desperately ill. And, just as an individual woman will assess the risk/benefit ratio differently depending on whether or not she is currently healthy, the policy decisions about whether drugs should be available to the public must depend on the health status of the population intended to benefit from the drug's availability.

But while I don't see a double standard in arguing that treatments for women with metastatic disease should be available even when the risk associated with taking them are higher than acceptable for healthy women, I do see a double standard operating in cancer treatment. It is best exemplified by a story. When I was evaluating my options for treatment after my first diagnosis in the fall of 1993, I consulted an very well respected oncologist in San Francisco. I was consider-

ing doing chemotherapy, and we discussed whether I should opt for CMF (cyclophosphamide, methotrexate, 5-fluorouracil) or a more aggressive course of AC (adriamycin, cyclophosphamide), the two chemotherapy treatments then most commonly given on an adjuvant basis for breast cancer.

The doctor told me that the studies that had been done showed that AC was a more effective treatment than CMF for node-positive breast cancer, and that a study comparing the treatments in node-negative patients like me was under way. He went on to say that, while there were no data yet, his instincts told him that there was no reason to expect AC to be less effective for node-negative patients than for node-positive ones, and he would therefore recommend that treatment. The lesson I took from the doctor's analysis was that, when it comes to chemotherapy, what drugs to use may be determined by instinct instead of science.

Yet when it comes to complementary or alternative therapies, most oncologists insist that there is no scientific basis to justify their use. While it may be understandable that western-trained doctors are more comfortable relying on their instincts with respect to conventional treatments than where less conventional approaches are concerned, this double standard is not in patients' best interest. Our doctors should be as schooled in — and as open to — holistic approaches to breast cancer treatment as they are with respect to the aggressive modalities of surgery, chemotherapy, and radiation.

The need for a broader approach to breast cancer treatment, and a more sophisticated public understanding of risks and benefits of new (and old) treatments, will be particularly apparent to activists during Breast Cancer Awareness Month, which we at BCA continue to call "Breast Cancer Industry Month." With the corporate sponsorship of AstraZeneca (manufacturer of tamoxifen, owner of cancer treatment centers, and, until earlier this year, manufacturer of carcinogenic pesticides), the airwaves and magazines will be filled throughout October with messages like "Get a mammogram to save your life" and "Breast cancer detected early is almost 100 percent curable." Hospitals and companies that want to show how much they care about women will sponsor a breast cancer day, claiming to inform the public about the latest "breakthroughs" in the "war against cancer." Every magazine with a significant female readership will focus on personal triumphs and tragedies, and on the promise of the latest research.

From the trenches of the war on cancer, the world looks decidedly less rosy. When the late Susan Claymon, one of BCA's founders,

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Breast Cancer Action

Mission Statement

Breast Cancer Action carries the voices of people affected by breast cancer to inspire and compel the changes necessary to end the breast cancer epidemic.

Core Principles and Values

1. We are a membership-based organization.
2. We honor each person's commitment and energy to our mission.
3. We are not afraid to examine all sides of all issues.
4. We cannot be bought.
5. We tell the truth about what we discover.
6. We serve individuals while reaching the broader population.
7. We value the involvement of grassroots activists throughout the country and around the world to further our mission.
8. We encourage people to participate fully in decisions relating to breast cancer.
9. We believe access to information is vital.
10. We recognize that structural changes in society are needed to accomplish our mission.

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Five Things I Learned at ASCO

By Lauren John

The annual meeting of the American Society of Clinical Oncology (ASCO) is part medical conference and part drug-industry trade show. Some 23,000 people, mostly oncologists, get together to share what they do and don't know about drug treatments for cancer. As a result, there's little or no information here about two key issues that our members care about: (1) environmental links to cancer and (2) complementary approaches to healing.

Why, then, was I in New Orleans a few months ago for this year's meeting? As a writer and a librarian, I was there to gather information and report back on treatment trends. So here are three new terms, one new initiative, and one advocacy measure I learned about — and some social commentary on the side.

Chemoprevention Cancer chemoprevention deals with pharmacological, nutritional, and/or hormonal methods of stopping the disease before it starts. Today, this means giving healthy people at high risk for breast cancer drugs like tamoxifen; in the future, it might mean giving them a breast cancer vaccine. In the best of all chemoprevention worlds, scientists could identify effective, nontoxic agents — and we would see research on soy products and herbs in addition to estrogen-blocking drugs.

An adjunct to the concept of chemoprevention is the idea that, in the near future, cancer may be seen as a chronic rather than deadly condition, and that we might treat it the way that we currently treat asthma or high blood pressure. In a lecture entitled "Chemoprevention in the 21st Century: Genetics, Risk Modeling, and Molecular Targets," award-winning cancer researcher Waun Ki Hong asked, "When we see patients with hypertension and [high cholesterol], what do we do? Do we wait until patients have [a heart attack] or stroke? No, we intervene accordingly."

Cancer genetics Although a number of genes have been linked to the development of breast cancer (e.g., BRCA1 and 2, p53), today only about 5 percent of breast cancers can be attributed to high-risk genes. Are there more cancer susceptibility genes that have yet to be identified? Can we develop better tests to find the genes we already know about? Who should be tested in the first place? And what

treatment options should women (and men) choose if they learn that they carry a breast cancer gene? (See *BCA Newsletters* #36 and 40 for more on this topic.) In addition to presentations on genetics discoveries, oncologists were offered a series of continuing education classes covering basic genetic science. The classes were very well attended.

Hormone blockade therapy This type of therapy shuts down the production of estrogen in the ovaries and blocks any remaining estrogen from binding to cellular receptors. Given that estrogen fuels cancer growth in estrogen-receptor-positive breast cancer patients, the idea is to prevent estrogen from "feeding" the cancer. Once again, tamoxifen plays a starring role here.

The new twist this year at ASCO was the concept that, for some breast cancer patients, hormone blockade therapy could be used instead of chemotherapy — with similar results and less severe side effects. (Right now, many breast cancer patients take tamoxifen *after* they undergo chemotherapy.)

The idea that hormone blockade therapy may be as effective as chemotherapy was presented along with the results of a randomized French study in which 333 node-positive premenopausal women received either of the following treatments: (a) a three-year regimen of tamoxifen and Triptoreline, a drug that blocks the effects of leuteinizing hormones, or (b) a more traditional, six-month chemotherapy regimen of epirubicin, cyclophosphamide, and fluorouracil. The study was conducted from 1990 to 1998.¹

After a median follow-up of four and a half years, there were 22 relapses (13.5 percent) in women using hormone blockade versus 32 relapses (10 percent) in the group using chemotherapy. Deaths occurred in seven patients (4.3 percent) receiving hormone blockade therapy, while 13 patients (7.7 percent) in the group that received traditional chemotherapy died.

Overall survival was 97 percent in the hormone blockade group, compared with 93 percent in chemotherapy users. After three years, menopause was reversed in half the patients who received hormone blockade therapy.

Hormone blockade treatment is offered more often in Europe than in the United States, where patients are far more likely to be offered chemotherapy.

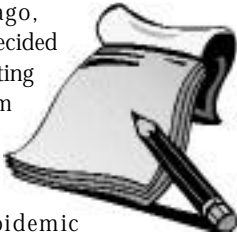
National Initiative on Cancer Care Quality

Announced at ASCO, this is the first phase of what will hopefully become a long-term program to establish national standards for

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A Change in Policy

Two years ago, when BCA decided to stop accepting contributions from companies that we knew or suspected profited from the breast cancer epidemic (pharmaceutical companies and corporate polluters, for instance), we knew that our policy would present challenges. To start with, individuals' gifts are often matched by their corporate employers — and we felt that we should not be prohibited from accepting *matching* gifts stimulated by an individual's donation, regardless of the company's business. Given the spirit in which such gifts are initiated, we felt that we could accept such contributions and still ensure our accountability to our members.



But several months ago we encountered an unexpected dilemma: We received a check that, under ordinary circumstances, we would have had to decline. It was from Bechtel, a corporation known to contribute to environmental degradation. One of the company's employees, whose wife had died of breast cancer, had asked that contributions be made to Breast Cancer Action in her memory in lieu of gifts — and his employer was honoring that request.

The BCA board of directors considered the situation at length, taking into account both our responsibility to our constituents and our desire to honor the wishes of families deeply affected by breast cancer. Ultimately, we decided to revise our corporate contributions policy to reflect the complexity of this issue. (See *BCA Newsletter* #50, or contact the office, for a copy of the original policy.)

The revised policy indicates that BCA will not be prohibited from "accepting matching gifts from corporations that are initiated by employees or corporate contributions made in memory of someone at the request of the decedent or her or his family."

To further alleviate any concerns about accepting these donations that would otherwise violate our policy, we added that they should be "earmarked specifically for BCA's work on environmental issues or activities related to the organization's ongoing promotion of the precautionary principle."

We invite you to let us know what you think of this change. Please feel free to call the BCA office or e-mail info@bcaction.org with your thoughts or to request a copy of the full policy. ♦

The First Look



I miss my breast every day.

Being one-breasted isn't difficult, but that doesn't mean it's easy. There is one moment every day — when I remove my pajamas to step into the bathtub in the morning or when I pull my shirt over my head to undress for the night — when I am still shocked to see my asymmetrical chest.

The mastectomy was my fourth surgery: two excisional biopsies, one lumpectomy, eight weeks of radiation, and finally, two-and-a-half years later, the amputation. I fought hard to keep my breast and gave it up only when it seemed absolutely necessary. There is no way of knowing if it was — the cancer metastasized to my spine less than 12 months later.

This photograph was taken six weeks after the mastectomy. Within two years, the thin red line faded to white. The skin is supple after daily self-massage; the left side of my chest is a series of soft and hard ripples. I'm no longer surprised at how loud my heartbeat sounds without the soft cushion of my breast to muffle it. I often wear jewelry where my breast used to be; I do not wear a prosthesis. I go naked to the women's bath and wonder what the bathers think and feel when they see me. Am I their worst fear? Do they silently applaud me for my courage or resent me for making them look at something they would rather not confront?

I feel strongly that we *must* be seen. Breast cancer, and the effects of the treatment, have been hidden long enough. The wounds are quickly covered with "breast forms" or "reconstruction," as if they are a secret we must keep from each other and the world, as if the solution is merely cosmetic. An advertisement I have seen too often in magazines shows a diverse group of women with breast cancer who have, according to the advertiser, boosted their self-esteem by learning to hide their cancer with cosmetics, wigs, and creative ways of wearing scarves. We may laugh at the sheer absurdity of this message, but it is as insidious as breast cancer itself.

There is still no cure for breast cancer. All the technology intended to make us "beautiful" after we have been cut, radiated, and filled with toxic chemicals does not alter that fact. Until the real causes of the disease — the human-made, environmental causes — are addressed with commitment and sincerity, the word *prevention* holds no meaning.

I don't know if I will die from breast cancer, but I do know that, day to day, I am living with it.
— Merijane

Excerpted with permission from The First Look (University of Illinois Press, 2000), a book of photographs by Amelia Davis (who chose to keep her subjects anonymous). BCA will sponsor an event in honor of the book, including a discussion of the issues raised by the images, on Thursday, October 19, at the Hang Gallery in San Francisco. Call the BCA office at 415/243-9301 for more information.

Stage IV at 35 Ellen Lew's Journey to BCA

By Carrie Spector

Opening Day at San Francisco's new ballpark was cause for celebration for many Bay Area Giants fans, but it was a particularly poignant moment for Breast Cancer Action board secretary Ellen Lew. Diagnosed with Stage IV metastatic breast cancer four years ago at age 35, Ellen — who has been a Giants fan since adolescence and attends as many as 30 games a season — wasn't sure she would live to see the first pitch at Pacific Bell Park last spring.

Her first encounter with breast cancer came in 1992, when she found a lump in her right breast while showering. She was only 31, but "my intuition told me that something was wrong," she says. She made an appointment with a doctor, who referred her to a surgeon for a biopsy.

The biopsy indicated malignant cells. "I felt the floor go out from under me when the surgeon called me with the results," she remembers. Ellen bought a copy of *Dr. Susan Love's Breast Book*, sought a second opinion (which confirmed the first), then went ahead with treatment — a modified radical mastectomy with axillary node dissection. The surgery showed that the sampled lymph nodes were clear, and she was diagnosed with Stage I breast cancer. She was then further treated with a six-month course of adjuvant chemotherapy.

In 1996, when she was 35, Ellen drew her oncologist's attention to swollen lymph nodes on the left side of her neck and collarbone area. After another biopsy and blood test, including a CA15-3 tumor marker, she was diagnosed with metastasis to the lymph nodes.

"I was scared," she says. At Stage IV, "control — not cure — becomes the primary goal." Fortunately, a chest x-ray and bone scan came back clear of metastases.

She then sought out BCA cofounder Susan Claymon, who was also battling Stage IV metastatic disease at the time (and, as most readers of this newsletter know, died earlier this year after a 15-year struggle with the disease). The two had first met in 1992, and Ellen knew of Claymon's "wisdom and supportiveness," she recalls. "During a long phone call,

she gave me support and advice, and she referred me to other resources."

The hormone-receptor status of Ellen's tumor was both ER and PR positive, meaning that she was likely to be responsive to hor-



monal treatment — uncommon for a premenopausal woman. She ultimately opted for monthly injections of Lupron (chemical castration) and tamoxifen, a combination that swiftly brought her into menopause. (Her chemotherapy treatment after the first diagnosis hadn't.) She also attended a week-long retreat in 1998 at Commonweal, a health and environmental research center in Bolinas, California, and used Chinese herbs to boost her immune system.

"I've had an extremely good response to the treatment," she says, recalling a quote from a prostate cancer patient: "I am a chemical eunuch, but so what? I live."

In a number of ways, she considers herself blessed. She appreciates the quality of life she has been able to maintain, now living basically without symptoms and having gone nearly four years without a recurrence. Family, friends, and support groups helped her to recognize and seek out support when she needed it, and the disease has brought her to develop and deepen her sense of faith. She is also grateful for having the "privilege," she says, of "knowing and meeting people who taught me about life by their example" — and she has become involved on a political level in ways she never would have expected.

Ellen first heard about Breast Cancer Action just a couple of years after the organization was founded. She was attending a support group at the Cancer Support Community in San Francisco after her first diagnosis, and soon began receiving the newsletter and attending various BCA events.

"I found myself agreeing with BCA's positions on the issues," she says, adding that BCA was one of the first groups she found that addressed the precautionary principle of public health. She particularly appreciated the organization's five task forces, which give individuals the opportunity to get involved without making a huge time commitment. She also remembers attending a lecture geared toward the Chinese community and being affected by the presence of Susan Claymon, who had come to support the event even though she was exhausted from treatment at the time.

Ellen has found that, in trying to make the best use of her own resources, making personal decisions has become more difficult. With more than 16 years' professional experience in payroll and accounting, she was recently laid off from Levi Strauss & Co. when the company moved part of its accounting department out of state. While she is extremely conscious of her vulnerability to employment and insurance discrimination, she is more concerned with the way her time is spent.

Earlier this year her tumor marker went up, indicating the possibility of cancer-cell growth — a sobering reminder of the uncertainty that breast cancer has brought to her life. She now seeks not only to trust her instincts and to make choices that feel meaningful, but also to allow herself time and energy to pursue the things that feed her in deeper ways: writing, creating watercolors, drawing — and, of course, baseball. ♦

BCA Gets Rewired

If you haven't checked out our Web site lately, you'll be surprised at the changes we're making. Soon you can search our newsletter archives by topic or keyword, make a donation, volunteer for a task force or other activity, read about current campaigns, and much more — online. Take a trip to www.bcaction.org to get informed and involved! A huge thanks to Evan Deerfield of Cobalt Blue (www.cobaltbluesf.com) for spearheading our spectacular relaunch, and to Kristi Habadanck and Susanne Rotando for the funds that made it possible.

Saline Implants: For Better or for Worse

By Lauren John

Ilan Reich does not know how many women use his company's saline-filled breast implants for breast reconstruction after cancer surgery. But they must benefit from the implants, he says, because — despite complications ranging from infection to deflation to hardening — women keep buying them. What greater proof of customer satisfaction could there be, Reich asks, than the fact that so many women opt to replace their saline implants rather than forgo them entirely — even if the product has failed?

Reich is the president of Inamed Inc., which is the parent company of the McGhan Medical Corporation, a Santa Barbara, California-based saline implant manufacturer. McGhan Medical is one of two companies that received Food and Drug Administration approval for its saline implants this May. (The second manufacturer, also based in Santa Barbara, is the Mentor Corporation.)

The American Society of Plastic and Reconstructive Surgery reports that close to 70,000 women had breast reconstruction following mastectomy in 1998, up from about 30,000 reconstruction procedures done in 1992. About a fifth of this group — close to 14,000 women — chose to have saline implants.

Imaginis.net, an Internet health information site, offers similar statistics: According to the site, approximately 15,000 breast cancer patients elected to have saline breast implants after mastectomy in 1999. Meanwhile, the site reports, about 135,000 women received saline implants for cosmetic reasons.

Over the past five years, McGhan Medical has run three clinical trials to determine the short-term and most common risks associated with saline implants. Of the 4,013 women enrolled in the studies, 462 were given the implants after reconstruction. About half of the reconstruction patients, or 225 women, were enrolled in a one-year trial (and only about two-thirds returned for their one-year follow-up visit). The rest of the reconstruction patients under study — 237 women — were enrolled in a five-year study, with 76 percent returning for their three-year follow-up visit. (The third study examined only women who had undergone augmentation.)

Could these studies provide enough information to determine whether the implants were safe for women who have had

breast reconstruction? And was three years long enough to get answers?

"The FDA thought it was," Reich responds confidently.

Hazardous to Your Health?

In May the FDA approved the implants manufactured by the two Santa Barbara-based companies even though it publicly acknowledged that the devices have "relatively high complication and failure rates," particularly for breast cancer patients.¹



A ruptured saline implant, photographed by breast cancer activist Anne Stansell

"Women should understand that breast implants do not last a lifetime," David Feigal, head of the FDA's Center for Devices and Radiological Health, said in a public statement after their approval was announced. "It is clear that there is a possibility that a substantial number of women who get these implants will require additional surgery at some point to remove or replace their implants because of complications," he continued.²

Using data from several Mentor and McGhan Medical studies, the FDA concluded that 13 to 21 percent of cosmetic-surgery patients and 40 percent of breast cancer patients were likely to need repeat surgeries within one to three years of receiving saline implants. In some cases, an old implant is replaced with a new one after the original deflates. In other instances, when scar tissue or skin that normally forms around an implant tightens and squeezes the implant (a process plastic surgeons refer to as *capsular contracture*), surgery would be needed to

remove scar tissue. In fact, several studies show that women who receive implants for breast reconstruction after mastectomy are twice as likely to suffer complications than women who undergo augmentation.

Saline breast implants can also cause dimpling and puckering at the implant site, loss of nipple sensation (which is usually preserved for women who have undergone augmentation), and asymmetry.

In a three-year study of 416 women who received Mentor implants for breast reconstruction, 40 percent needed additional surgery and 27 percent asked that the implants be removed, usually because of complications such as infections, pain, hardening, or deflation. (In some cases, the implants had to be removed because they had ruptured and leaked. In fact, one study showed that about 9 percent of Mentor implants given to breast cancer patients ruptured and deflated within three years.)

Doctors Warned — Not Patients

The FDA approved the saline implants with the stipulation that women be warned of their risks. The warnings are slated to come in the form of inserts or educational materials that will be included in or on the implants' boxes — meaning that patients are left out of the direct flow of information. In many cases, then, it will be up to doctors to inform patients of the risks.

Some patients, of course, will take to the Internet for consumer information, and the FDA has posted the warnings at its site (www.fda.gov). And McGhan Medical has posted the same warnings prominently on its Web site (www.mcghan.com), in an article entitled "Saline-Filled Breast Implant Surgery: Making an Informed Decision." As of press time, the Mentor Corporation had yet to post any warnings at its site (www.mentor-corp.com). Diane Hart, patient services manager at Mentor, says that the company is in the process of revising its educational materials to reflect the new FDA guidelines. Once they are updated, information packets will be sent directly to patients who request them (call 805/879-6000).

In the past, Mentor has made a video titled "Options in Reconstruction" available to doctors and women's health centers (including the Community Breast Health Project in Palo Alto, California, whose cofounder, breast surgeon Ellen Mahoney, praises it as "one of the most honest videos I have seen.") When I asked Hart whether I could obtain a copy, she told me that Mentor was considering whether to update the video, adding that it is not a high priority right now. If the company decides to update it, copies will be sent to breast cancer

organizations and libraries. But Mentor will not send the video directly to patients because of "cost considerations," Hart says.

On the subject of cost considerations, it's worth noting that both Mentor and McGhan stand to profit substantially from the FDA ruling. "This is an enormous positive for the breast implant industry," John Calcagnini, an analyst at the investment-banking firm of CIBC World Markets, told Reuters. "We think both stocks [Mentor and McGhan] are undervalued."³

The Women's Health and Cancer Rights Act of 1998 now federally mandates insurance coverage for breast reconstruction following a mastectomy. So "we will continue to see even more women opting for reconstruction following mastectomy," says Paul Schnur, president of the American Society of Plastic Surgery.⁴

A lot of women, some feminists among them, would be angry if the FDA were to take saline implants off the market entirely — especially since, for better or for worse, many have been using the devices for some ten years now. What would they do if they needed to replace their implants and found that they were no longer available?

"Women are grown-ups and capable of making the decision of whether or not they want saline breast implants," breast surgeon Susan Love, author of *Dr. Susan Love's Breast Book*, told the *New York Post Online*. "There's no evidence that they're life-threatening, and as long as women are completely informed of the risks that they may rupture or cause an infection, there's no reason why they shouldn't remain on the market."⁵

In January, several months before the FDA approved the implants, BCA urged the agency not to do so until the devices' long-term safety could be proven.

Building a Better Implant

The FDA could have continued to keep the saline implants on the market without giving them a formal stamp of approval, says Diana Zuckerman, director of the National Center for Policy Research for Women and Families (CPR), an advocacy group based in Washington, D.C. "By approving these saline implants despite their serious problems, the FDA has eliminated the incentive for a company to make a better product."

Zuckerman believes that the long-term risks of breast implants have not been adequately studied and that women are not getting the unbiased information necessary to make an informed choice. She says that if the FDA had allowed saline implant manufacturers to keep their products on the market

(with the assurance that patients would be clearly informed of the implants' risks at least a few days before surgery), there might have been more incentive for companies to step up their research and development. At the very least, we might have seen studies to determine which of the brands and models of saline implants were most reliable.

Many women who have saline implants are surprised to learn that the FDA had never approved them until May of this year.

Saline breast implants have been sold in the United States for more than 25 years. In fact, they hit the market before the FDA even began regulating medical devices. But many women who have breast implants — such as Jo Muller, a BCA member from Orinda, California — are surprised to learn that the FDA had never formally approved any of the brands until May of this year. "You would think that if your plastic surgeon offered it to you, it had been approved," Muller says.

The FDA became interested in saline implants about seven years ago, after safety concerns and multiple lawsuits prompted the agency to ban *silicone* breast implants for most women in the United States. (You can still receive silicone implants in some cases if you agree to participate in a clinical trial, and

they are still available in some European countries). Saline implants are considered safer than silicone because if a saline implant bursts, the salt water is absorbed by the body. Silicone gel, on the other hand, moves into other parts of the body and is difficult to remove.

From a cosmetic standpoint, when there are no complications, saline implants can look very good. The surgery is also far less extensive and invasive than, for instance, the TRAM flap procedure, in which the patient's own muscle is used to create new breast shapes.

So if you are faced with a decision about reconstructive surgery and saline implants are an option, what should you do?

Breast and plastic surgeons should offer counseling that includes a discussion of risks and alternatives, says the Community Breast Health Project's Ellen Mahoney. "Saline implants do make clothes-wearing easier, and though they are not perfect, they are good enough to give some women the feeling of wholeness that they need," she says. "But they are not for everyone, and we need to make sure that women know about other kinds of reconstructive surgery — like [LAT flaps], and TRAMs, and the option for no reconstruction, which is something that often gets left out."

The best advice that Jo Muller can offer women faced with this decision is to talk —

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Breast Friend — and Bust — of the Month

Three cheers for 3M, the consumer products company famous for developing such beloved office products as Scotch tape and the Post-It note. The company recently announced that it would stop making Scotchgard, a spray used to protect fabric and rugs from stains, after tests showed that a chemical compound in the product lingers in the environment and human blood. (The compound, known as perfluorooctanyl, is used in many other products, including DuPont's Teflon.) There isn't any evidence yet that the compound is hazardous to humans, so BCA is delighted to file 3M's announcement under *precautionary principle in action*.

BCA supporter Diane Sabin was not delighted, meanwhile, to find a particular direct mail insurance pitch in her mailbox.

"You'll be glad to have it if cancer strikes," the solicitation began, "and doubly glad if it doesn't!" Here's the deal: If you're a Discover Card holder who's never had cancer, you can take out an insurance policy with Union Fidelity that will cover treatment if you're diagnosed with the disease in the future. Your premiums will be refunded, however, for each consecutive ten-year period that you remain cancer-free.

Union Fidelity, which calls its coverage "a positive solution to the growing threat of cancer," makes a profit off subscribers who stay cancer-free by earning interest on their premiums. But it's a sad commentary on the state of the cancer epidemic when a notoriously competitive industry can cash in on the public's fear — and the very real possibility — of developing this damned disease.

Circadian Rhythms

continued from page 1

found lower breast cancer rates, as predicted, in this population; a third study did not.

Arendt also found no differences between melatonin levels in women with benign and malignant breast tumors (an American study has found a difference). Since melatonin levels diminish with age, Arendt stresses that epidemiological research should control for this variable. Small pilot studies are inherently limited but, as Arendt observes, "these studies are not cheap, and it's hard to get funding for a large, prospective study with negative pilot data."

Epidemiologist Richard Stevens, meanwhile, points to a study that found elevated breast cancer rates among Finnish flight attendants, noting that the incidence is too high to be accounted for solely by increased radiation exposure. Disruption of circadian rhythms might well be a causative factor in these cancers, he says. And alcohol disrupts sleep, which in turn could suppress melatonin, perhaps explaining why excessive alcohol consumption increases breast cancer risk.

Windows of Time

William Hrushesky, M.D., a clinical researcher at the Stratton VA Medical Center in Albany, New York, believes that research on cycles should extend beyond circadian rhythms to menstrual and seasonal cycles. We already know, he points out, about certain "windows of time" that can optimize the effectiveness of cancer therapy while reducing side effects. Cancer drugs should be administered in the morning, when bone marrow and gut proliferate at two to three times the night-time rate. In a study of women with ovarian cancer, optimal timing of chemotherapy improved efficacy from 11 to 44 percent. Performing breast surgery in the early luteal phase of the menstrual cycle (days 14-21) yields a 25 percent advantage in ten-year survival over surgery in other phases, he says, while mammography screening is less effective in the luteal phase. (The day menstrual bleeding begins is considered the first day of the cycle.) Pap smears for cervical cancer are more sensitive during the summer, Hrushesky says, and breast cancer is most often diagnosed in the spring.

"We are doing great harm because we ignore cycles," he charges. His work has been ridiculed and ignored, he says, because of inertia and linear thinking in the research community. Although five prospective studies on the timing of breast cancer treatments are

now in progress, he predicts that only one, an Italian study, is properly designed to yield meaningful results.

Translating the Data

While little of the research that exists on circadian rhythms is definitive and can be translated to real-world practice, some lends itself to an approach based on the best-available evidence. The good news is that starlight, moonlight, and lightning all fall outside the spectrum of light that depresses melatonin. Researchers speculate that the body is made aware of lighting not through vision but through another system in the retina — so if your bedroom window is next to a street light, eye shades or a light-tight blind are harmless ways to keep the melatonin flowing. Red-spectrum light is least disruptive and therefore best for night lights or clocks with illuminated time displays; blue-green light is most disruptive.

For advocates, research into circadian rhythms offers plenty of scope for action. Melatonin is a product that can't be patented, which suggests why research into its therapeutic potential is so sluggish. Also, circadian rhythms lie outside the realm of much of cancer research, so proposals are

more apt to flounder. Finally, as William Hrushesky argues, we need to put hard-won knowledge about "windows of time" to better use.

For me, the National Action Plan on Breast Cancer's workshop recalled an early radicalizing experience, a 1991 conference at which Congressional representative Pat Schroeder blasted cancer researchers for excluding women from clinical trials. Because women's cyclical physiology doesn't fit the linear shoe of fashionable science, she charged, "they even used male rats to study breast cancer." Finally, a critical mass of researchers is saying that cycles matter. ♦

Sharon Batt currently holds the Nancy Ruth chair in women's studies at Mount Saint Vincent University in Halifax. She is the author of Patient No More: The Politics of Breast Cancer (Gynergy Books, 1994) and cofounded Breast Cancer Action Montreal.

Celebrating a Decade of Action



Breast Cancer Action marked its tenth anniversary on July 20 with a party featuring the premiere performance of a theatrical civil action by Opera Piccola, a Bay Area theater company. The theater piece was developed to be taken to the street as an educational and organizing tool. Before the performance, BCA Executive Director Barbara Brenner (left) and Board President Jane Sprague Zones (right) led friends and supporters of the organization in an unexpectedly spirited homage to those who have died of breast cancer: a round of foot-stomping and cheers. "It's customary at breast cancer events to honor the spirit of those we have lost by observing a moment of silence," Brenner told the crowd of nearly 300. "But I've never believed that silence accomplishes anything."

¹ See the National Geophysical Data Center's Web site (www.ngdc.noaa.gov). Click on "DMSP Data Archive," then on "City Lights at Night," which will link you to a map showing nighttime lights around the world.

Saline Implants

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to their plastic surgeons, their breast surgeons, and other women who have gone through the procedure. (Muller invites readers to contact her through the BCA office; she received her saline implant a year and a half after undergoing a TRAM-flap procedure on the other side, in which abdominal muscles were used to build a new breast mound.)

Certainly, you should ask your surgeon for the information that the FDA requires Mentor and McGhan Medical to provide. Zuckerman cautions, however, that surgeons are rarely the most reliable source of information. "Most of the research on implants for reconstruction patients is not published," she says, "and the safety of the procedures varies, depending on the surgeon. There is no way for doctors to accurately convey the risks to their patients."

As long as you're talking, this is a good time to talk to Congress, too.

"There will not be any more FDA hearings [on saline implants] anytime soon, so the action is in Congress now," says Zuckerman, who initiated the congressional investigation of silicone implants about nine years ago. "Members of Congress need to hear about the need for legislation to ensure clear, prominently placed warnings on ads for implants. These warnings should have a box around them, the way that warnings on cigarette ads do."

The ads' warnings are likely to be "a page of tiny type like for prescription drugs, which nobody ever reads," Zuckerman says, adding that though the FDA will develop a brochure that warns of the risks, there is no guarantee that patients will ever see it.

Zuckerman urges activists to contact their legislators, as well as the co-chairs of the Congressional Caucus for Women's Issues, New York representatives Carolyn Maloney and Sue Kelly. Contact the Center for Policy Research for Women and Families at 202/216-9507 or cpr4wandf@aol.com (or visit www.cpr4womenandfamilies.org) for more information. ♦

¹ "FDA Says Two Saline Breast Implant Brands Safe," *Reuters News Service*, May 11, 2000.

² Woznicki, Katrina, "Warning Put on Breast Implants," *OnHealth.com*, May 12, 2000.

³ "Mentor Pushes Higher on Breast Implant Approval," *Reuters Company News*, May 11, 2000.

⁴ "Plastic Surgeons Support the Fight Against Breast Cancer: Breast Reconstruction Following Mastectomy Up 135 Percent," *Plastic Surgery Information Service* (www.plasticsurgery.org), October 1, 1999.

⁵ Levine, Hallie, "Women's Health Dilemma," *New York Post Online* (www.nypostonline.com/living/1344.htm)

Five Things I Learned at ASCO

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quality of cancer care. Over the next year and a half, researchers at Harvard University and the RAND Corporation will examine the quality of cancer care that a sample group of 300 breast cancer patients and 300 colorectal cancer patients received while being treated at hospitals in and around Los Angeles, Houston, and Cleveland.

Patients will be interviewed by telephone and asked to permit a review of their medical records, which will be kept confidential. Patients' care will be assessed by measures including the availability of facilities and technology, the speed with which they are diagnosed, and the outcomes of treatment.

The Susan G. Komen Breast Cancer Foundation — which sponsors the Race for the Cure and offers millions of dollars in breast cancer research grants each year — is providing half of the study's current \$2 million budget. As a result, breast cancer survivor Nancy Brinker (who started the Komen Foundation in honor of her sister Susan, who died of the disease) was the most recognizable consumer advocate at ASCO. Brinker has served as a national breast cancer advisor under both the Bush and Reagan administrations. She is impeccably groomed, and has

authored book chapters detailing how cosmetics and false eyelashes can be powerful tools in helping women to deal with the rigors of chemotherapy. Not surprisingly, Brinker comes across as deferential — perhaps too deferential — to the oncologists that her foundation is helping to support.

For example, while in a speech to ASCO, Brinker referred to her sister as "uneducated and unempowered" — she never once criticized her sister's provincial, small-town surgeon who told her "they got it all" and that he could "cure" her. (She is a bit harder on the surgeon — just a tiny bit — in her 1995 book, *The Race Is Run One Step at a Time: Every Woman's Guide to Taking Charge of Breast Cancer and My Personal Story*).

What to do when your health insurer denies drug coverage

A week before we left for ASCO, a woman called the BCA office asking for advice. She had developed blood clots while taking tamoxifen, and her oncologist wanted her to switch to Arimidex, a more expensive drug that unfortunately wasn't included in her insurance coverage.

I spoke with AstraZeneca drug reps at ASCO (who assumed I was a cancer doc) and gathered information from groups that might help her. One such group, the Patient

More Perspectives on ASCO

I spent a great deal of time at the ASCO conference asking myself, "What is the role of advocacy at this meeting?" There were about 23,000 oncologists from around the world, pharmaceutical industry representatives, and a handful of advocates. There was no predetermined way for advocates to connect with each other, nor with the doctors.

I saw my role as an observer, but also as someone to educate those present on the patient's perspective whenever and however possible. The doctors and scientists that I met seemed sincere in their desire to make a difference, and yet they also seemed quite removed.

"We must all remember that we could all be patients or healers at any time," said Larry Norton, chief of medical oncology at Memorial Sloan-Kettering Cancer Center, who participated in a forum about the challenges involved in enrolling patients in clinical trials.

This seems a vital perspective to carry, yet other conversations I participated in reflected only the separation between patients and doctors. One morning I shared breakfast with a group of other advocates and a young researcher. In conversation, while discussing his research, he said the words I had heard many times before: "The patient failed chemotherapy." I interrupted him to say that patients don't fail chemotherapy; chemotherapy fails. He laughed a bit uncomfortably. "Well, we don't talk that way in front of patients," he said.

"You just did," I responded.

Medical professionals need to be in touch with how and what they communicate to patients. I believe they are unaware and unwilling to take responsibility for their underlying assumptions, values, fears, and biases. Words do matter. We all could be patients or healers at any time. A deep understanding of this on all parts could transform the ways in which we all work together toward the same goals.

—Natalie Compagni Portis

Five Things I Learned at ASCO

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Advocate Foundation (www.npaf.org), based in Newport News, Virginia (800/532-5274), is a nonprofit organization that represents cancer patients facing hassles with health insurance coverage or employment discrimination.

At one exhibit booth I snagged a list of the pharmaceutical companies that sponsor drug services for patients who would other-

wise be unable to afford medication. The list — which contains contact information, guidelines, enrollment information, the oncologic drugs provided, and the supply that the companies will provide — appeared in the May 2000 issue of a new magazine called *Oncology Economics*, which covers the business side of cancer. The chief financial officer of a cancer center is more likely to get this magazine than you are, and there's no Web address for the article yet. But if you send me an e-mail (Laurenzina@aol.com) or

contact the BCA office, we will be glad to send you a copy. ♦

¹ H.H. Roche, Centre Claudius Regaud; P. Kerbat, Centre Eugene Marquis, Pharmacia Upjohn. "Complete Hormonal Blockade Versus Chemotherapy in Premenopausal Early-Stage Breast Cancer Patients With Positive Hormone-Receptor and 1-3 Node-Positive Tumor: Results of the Fasg 06 Trial" (unpublished).

More Perspectives on ASCO

Along with other BCA staff and activists, I spent a long four days traipsing through the seemingly unending halls of the New Orleans convention center, searching desperately and in vain for earth-shatteringly good news about breast cancer. Unlike the previous couple of years, when breast cancer chemoprevention (tamoxifen) and high-dose chemotherapy/autologous bone-marrow transplant (HDC/ABMT) were the hottest topics at this meeting, breast cancer issues were not the highlight this year. Instead, from where I sat, the major themes that ran through the meeting related to encouraging patients to enroll in clinical trials and an important new initiative by ASCO on quality of care in cancer treatment.

There was some breast cancer news (copies of the abstracts are available from the BCA office or online at www.asco.org):

— The FISH (fluorescence in situ hybridization) test appears to be a better way to evaluate which patients might benefit from Herceptin than the FDA-approved IHC (immunohistochemistry) test known as the HercepTest. Based on a study done by researchers at Genentech, which manufactures Herceptin, the FISH test will identify as eligible for Herceptin some patients who would be excluded, due to false negative results, using the IHC test. (Abstract 291)

— A shorter, more intense course of post-lumpectomy radiation may be just as effective as the current standard of a five-week, less-intense course in reducing the risk of a local recurrence of breast cancer. A five-year Canadian study showed that giving higher dosages of radiation over a three-week period is just as effective in terms of local recurrence rates as giving lower dosages for five weeks after a lumpectomy for node-negative disease. The U.S. radiologist who reviewed this study at the conference offered the opinion that doctors in this country would wait for longer follow-up before proceeding with a shorter course of radiation because of concerns about late onset toxicity (including lung and heart impacts) from the higher dosages of radiation. (Abstract 5)

— In a non-randomized trial, Herceptin alone as a first-line treatment for metastatic patients, instead of chemotherapy, appears to be as effective as Herceptin plus chemotherapy. (Abstract 275)

— A randomized study comparing adriamycin plus cyclophosphamide (AC) to cyclophosphamide plus methotrexate plus 5-fluorouracil (CMF) for node-negative, ER-negative breast cancer patients showed no difference in survival rates between the two groups. Adding tamoxifen to the chemotherapy treatments did not change the survival rates. (Abstract 277)

— In a short-term (four-week) study, the non-hormone-based antidepressant drug venlafaxine (Effexor) reduced hot flashes by 60 percent. The drug is one of a class known as selective serotonin-reuptake inhibitors, or SSRIs. (Abstract 4)

So while there was not much interesting news for breast cancer patients during the meeting, there were things that struck me as noteworthy:

— The vast majority of the scientific awards presented on the first day of the meeting were underwritten by pharmaceutical companies. I found this fact ironic in light of a recent editorial in the *New England Journal of Medicine* about the dangers posed to medical research by conflicts of interest.

— The most important award given at the ASCO meeting is the David A. Karnofsky Memorial Award. Karnofsky introduced the concept of chemotherapy in cancer, initiating studies using mustard gas. In 1969 he died of lung cancer, which, according to the person who presented the award, Karnofsky's friends are sure was caused by the mustard gas. This was as close as anything at ASCO came to identifying things that might cause cancer. It is notable that the most significant award given honors the person who introduced chemotherapy. Maybe it should be renamed the Mustard Gas Award.

— Nancy Brinker, president of the Susan G. Komen Foundation, declared that the biggest barrier to patient participation in clinical trials is failure of insurance companies to cover routine patient costs. I found that a rather astounding assertion, given the history of abuse of public trust in clinical trials in this country. It strikes me as just as likely that public mistrust explains the low trial enrollment rates, and that it will be necessary to address the reasons for that mistrust if we are to have any hope of increasing participation.

— The vast majority of the breast cancer poster presentations focused on new chemotherapy combinations. In light of this, it was refreshing to hear Clifford Huddis of Memorial Sloan-Kettering tell a room crowded with cancer doctors that we need to be looking at new modalities for treating metastatic disease.

— Ian Tannock, a British scientist who commented on studies presented at the plenary session, gave a stunningly frank talk about the likelihood of false-positive trial results in cancer treatment research, where the expectation of a positive result is low. (The South African HDC/ABMT study was a good example.) Tannock went on to point out that ASCO's plenary sessions, like many medical journals, suffer from selection bias in favor of positive studies.

—Barbara A. Brenner

Call for Subjects

Are you a lesbian who has had breast cancer in the last five years? Research volunteers are needed for phone interviews to discuss quality of life issues, emotional experiences, and the availability of resources and support. Participants earn \$20 for the one-hour interview, and all responses will be kept confidential. The University of Chicago and the Women's Research Committee of Howard Brown Health Center are conducting the study. For more information, call Patty Delaney, project coordinator, toll-free at 877/897-2777.

Studies show that support-group participation improves the quality of life of breast cancer patients — but does the leadership, format, or model of the support group make a difference? Researchers are seeking participants to help them assess the effectiveness of two major community-based support programs, and to determine which type best fits the needs of different women.

If you are a breast cancer patient with no evidence of metastasis or recurrence, and you are not more than 18 months from the end of your initial treatment (and not currently in a cancer support group), you qualify for this study on community cancer support.

Participants are randomly assigned to a San Francisco Bay Area support group, then assessed at baseline and four, eight, and 12-month intervals by interviews and questionnaires designed to measure mood disturbance, coping, social support, demographics, and group environment. Each participant receives \$40 for the four completed assessments. For more information, contact Vickie Chang, project coordinator, at 650/723-2688 or vickiec@stanford.edu. ♦

Bioneers for Change

Samuel Epstein, M.D., professor of occupational and environmental medicine at the University of Illinois and author of *The Politics of Cancer*, will be among the speakers at this year's Bioneers Conference, which takes place October 20-22 in San Rafael, California. The annual conference (\$100-\$295) brings together visionaries with practical solutions for our most pressing environmental and cultural crises. For more information, call 877/246-6337 (toll-free), e-mail chisf@bioneers.org, or visit www.bioneers.org.

Letters to the Editor

Re "Thermography: An Alternative to Mammography?" by Lauren John (July/August):

I appreciate that information needs to be shared on any advances to diagnosing breast cancer. I congratulate BCA for putting a question mark at the end of the title, but I have concerns associated with what appears to be a rebuke to radiologists.

As a mammographer dedicated to consulting and education, I would like to clarify some issues. [The author quotes a journalist who wrote that] "of course, radiologists have major investments in mammographic equipment ... and [they] consider surgery an imperative in virtually all cases."

Radiologists normally are hired to do the interpretations and do not "own" the equipment. Radiologists do not participate in the actual surgical procedure, so it is not monetarily driven when they do recommend surgery. Radiologists have consistently recommended alternative diagnostic evaluations to reduce the need for invasive surgical procedures, including ultrasound and MRI.

I am sure your readership is not aware that the reimbursement rate for a screening mammography often does not recover the costs involved. The regulatory demands of mammography are expensive and include personnel training and continuing education, equipment requirements and evaluations, patient and provider communication, and yearly federal inspections. I would doubt that many practitioners in any other field, including chiropractic, would be willing to go through such rigorous appraisals for such low reimbursements.

The article suggests that those who perform mammography are preventing the advance of other modalities. But radiologists often recommend that companies look at new approaches and welcome any alternative diagnostic modality that would help to ensure accuracy of results, aid in earlier detection, save lives, and lower the costs of finding breast cancer.

Radiologists are often not held in as high esteem as other specialists. They

usually are not chosen to head multi-modal



ity departments. The sued more than any other specialists. Radiologists dedicated to mammography should be congratulated for continuing to practice at all.

In closing, if thermography has been of such significant value for so many years, what is holding back clinical trails to obtain FDA approval?

I promise you that radiologists would welcome a better method for diagnosing breast cancer if and when it is correlated to do this — not just because someone says it can.

Regards,
Bonnie Rush, RT(R)(M)(QM)
President, Breast Imaging Specialists
San Diego

I would like to be removed from your mailing list as a result of my outrage at an article in your [May/June] newsletter. In it you took the American Cancer Society to task for spending money on a publicity campaign. I did not like the tone of your article, and I truly felt as if your efforts could be better spent working in a positive vein rather than devoting time and space to criticizing and tearing down another organization that is devoted to fighting this dreaded disease. You may not approve of their methods, but I don't see what you did as a positive thing. If within our own troops there is such negativity, how can we work toward the same goals?

I am a survivor, and each year I am personally involved with the fight in many ways. Please try and focus on the positive.

Ailya Rose

We'd like to hear your reaction to anything you've read in this newsletter. Write to us at 55 New Montgomery, Suite 323, San Francisco, CA 94105, or e-mail CSpector@bcaction.org.

Running Miles

It was six in the morning when Jennifer Miles (pictured at right) took off for a run along Northern California's American River. But this was no ordinary morning jog: With pledges secured from friends and family, Jennifer had expanded a personal challenge — a 50-mile marathon — into a fund-raiser for Breast Cancer Action.

It was an usually warm spring day; the temperature reached 86 degrees, and there was only a slight breeze to cool her and the other runners off. "The last ten miles were rough," she recalls. "My stomach was feeling the effects of running eight-plus hours in the heat." But she hung in there, and in just over ten hours after her early-morning start, she made it to the finish line.

What's more, she raised \$2,525 for BCA. "It meant a lot to me," she says, "and it will mean a lot to the people who will benefit from the work of Breast Cancer Action." ♦



We welcome other inspired ideas about ways to support our work. Call Melissa White, Development Program Manager, at the BCA office, or e-mail MWhite@bcaction.org.

Many Ways to Help BCA

Shop for a Cause Catherine Jane Mendoza is donating a portion of the proceeds from the October sales at her San Francisco clothing boutique to BCA. If you live in the Bay Area, stop by her store, Catherine Jane, at 1234 Ninth Ave. and treat yourself to some fine clothing. For more information, call the shop at 415/664-1855.

Creative Recycling Bay Area residents can drop off unwanted clothes and household items at the Community Thrift Store (625 Valencia, at 18th St.) and ask that the proceeds be donated to BCA. Call the store first at 415/861-4910 to make sure the merchandise you would like to donate will be accepted.

Strike Out Breast Cancer This annual bowling night, organized by the Universal Care Foundation, is always a blast — and BCA is a beneficiary. We would love to see you knocking down pins this year! See the calendar item on page 1 for more information.

Susan Claymon Advocacy Fund Established in honor of the BCA cofounder who died earlier this year, this fund has surpassed \$13,200. All gifts made to the fund will be used to support advocacy work done outside the San Francisco Bay Area: supporting outreach efforts around the country, and sending staff and volunteers to scientific conferences to ensure that the voices of people living with breast cancer are heard by the medical and scientific communities.

Tenth Anniversary Campaign Generous donors and sponsors are giving special gifts in honor of BCA's decade of activism. It's not too late for you to help us mark this important milestone!

Workplace Giving Many companies offer their employees a simple way to donate to charity: automatic payroll deduction. Some companies will match — even double-match — your workplace gift. Please consider making a gift to BCA through your workplace this year, and ask your company about matching it.

For more information about any of BCA's fund-raising programs, contact Melissa White, Development Program Manager, at 415/243-9301, ext. 15 (toll free at 877/278-6722) or at MWhite@bcaction.org. BCA is a registered California 501(c)3 nonprofit organization. We accept cash, checks, Visa, MasterCard, Discover, and gifts of stock.

Drug Dangers

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spoke about patient advocacy to the President's Cancer Panel in 1991, she highlighted a number of points that resonate as loudly today as they did nearly ten years ago:

There is no cure. Five-year survival (the statistic that is the basis for the October chant that "breast cancer detected early is almost 100 percent curable") is not a cure.

We do not know the causes of breast cancer. With the exception of radiation, this is still a true statement.

The incidence of the disease is skyrocketing in young women.

There is limited emphasis on prevention. Only chemoprevention gets attention from the dominant medical and scientific community. Strategies that will identify and begin to eradicate the causes of breast cancer are largely rejected or ignored.

Detection methods have limitations. As Susan said, "We have to tell the truth about the benefits and limitations of screening mammography," and about the need for a more effective, less invasive, and universally accessible detection method.

Advances in treatment methods are not proceeding quickly enough. The cure has been around the corner for more than a century, and 44,000 deaths every year from breast cancer are proof that the cure is still out of sight.

There is minimal attention to environmental concerns by the medical establishment. Instead, we hear about the promise of genetic research and the importance of studying the "gene/environment" connection.

Treatment costs are increasing, while insurance coverage is less and less available.

Issues of universal access to quality health care are critical, particularly for medically underserved and uninsured people.

As long as these issues need to be stated and addressed, Breast Cancer Action's work will continue. The growth of BCA — and the increasing understanding among our members and coalition partners that fundamental changes in society need to take place before we can solve the breast cancer problem — is a testament to the vision of our founders. It is also evidence of our commitment to countering the simplistic messages that the general public hears about breast cancer year-round, and especially in October. ♦

Glossary

To make this newsletter more accessible, we provide a glossary with each issue.

In some cases, explanations will be oversimplified. For detailed definitions, please consult a medical dictionary.



adjuvant therapy therapy given after a primary treatment (such as surgery to remove cancer), to reduce the chances of a recurrence

axillary lymph node dissection surgical removal of lymph nodes in the armpit area

biopsy removal of tissue, done either with a needle or surgery

BRCA-1 and BRCA-2 normal genes, which can carry a mutation that may increase a person's risk of developing breast cancer

carcinogen substance that causes cancer

chemoprevention the use of drugs or other substances to reduce an individual's risk of developing cancer

chronobiology the study of the timing of biological events, especially those that are repetitive or occur in cycles

cytotoxic causing the death of cells

first-line treatment a drug or other therapy offered initially following diagnosis

Herceptin drug that targets a genetically produced protein known as Her-2/neu, which is found in some cases of breast cancer. Herceptin delays tumor progression and extends life for some women with breast cancer whose tumors produce excessive amounts of the protein

holistic an approach to treatment that involves considering the entire body as a complete system rather than focusing on particular body parts or systems

in vitro in an artificial environment outside of living organisms

LAT (latissimus dorsi) flap breast reconstruction procedure in which muscle, fat, and skin from a patient's back is tunneled through the armpit and attached over the pectoral muscle, making a pocket for a breast implant

luteal phase anytime other than the third through twelfth days of the menstrual cycle. Days 14 through 21 are considered the "early luteal" stage

luteinizing hormone hormone produced by the pituitary gland that helps control the menstrual cycle

lymph nodes glands found throughout the body that fight harmful invaders such as bacteria. The presence of cancer cells in lymph nodes generally indicates that cancer is more likely to spread elsewhere in the body

malignant cancerous

mastectomy surgical removal of a breast

metastasis spread of cancer from its original site to another part of the body

non-randomized trial a research study in which participants are assigned deliberately, not by chance, to either "study" or "control" groups. Participants in the study group receive an experimental treatment, while those in the control group do not

oncology the study of cancer

oxidation a chemical reaction, involving oxygen, that damages cells

pesticides chemicals used to kill insects

pharmacological involving the use of drugs

radiologist an individual specializing in the use of X-rays to diagnose or treat disease

remission disappearance of detectable disease

saline salt water

silicone a synthetic plastic material

tamoxifen a drug (sold under the trade name Nolvadex) that blocks hormones from stimulating cell or tumor growth, reducing the risk of a breast cancer recurrence for women whose breast cancer is receptive to estrogen

Expression of Gratitude

We couldn't do what we do without the support of many individuals. Thanks to our office volunteers: Barbara Anger, Connie Baker-Cohn, Ellen Bunning, Amy Friedman, Dorothy Geoghagan, Andrea Guibao, Marge Hanson, Barbara Marre, Jo Muller, Jennifer Mhyre, Lisa Rico, Ed Romero, Ingrid Schultheis, Michelle Seville, Linn Swaim, Susan and Megan Vanneman, Robert Waugh, Kelly Wong, and Barbara Wray.

Thanks also to our Development Task Force: Peg Stone, Belle Shayer, Renetia Martin, Gail Kaufman, Hilary Crosby, Susan Stone, and Natalie Compagni Portis. More thanks to Scott Abbott and Susan Liroff, our volunteer Webmasters; and to Courtney for her consulting services on personnel issues.

The following groups and individuals have made a range of BCA benefit events happen, helping to raise the funds that make our work possible: Davis Riemer, James Geras of Atelier 142, Marie and Michael Powers of the Power Exchange, Christy Coté, Scott Patterson, and the Allegro Ballroom.

BCA is always seeking volunteers to assist with a wide range of projects. To find out how you can help, call our volunteer coordinator, Suzi Kalmus, at 415/243-9301 (or 877/278-6722, toll-free), or e-mail SKalmus@bcaction.org.

Pesticide Pressure

Activists will come together to strategize on pesticide reform, environmental health, genetic engineering, and corporate control of agriculture at "Taking Back Our Food, Farms, and Playgrounds," a conference taking place October 6 to 8 in Redwood City, California (just south of San Francisco). For more information, call conference coordinator Christine Lee at 415/981-6205 ext. 382 or e-mail ctlee4@panna.org.

Writers Wanted

BCA is seeking volunteer writers for our newsletter. Writers should have journalistic or professional writing experience and interest in breast cancer issues. For more information, call Carrie Spector at the BCA office, or e-mail CSpector@bcaction.org.

Donations in Honor

BCA gratefully acknowledges donations made in honor of the following individuals between April 18 and July 9, 2000.

All who live with the disease
from Joan and Charles Demitz

All women
from Cary Hirschfield

Cathie Alvarado
from Regina Gabrielle

Pauline Attard
from Barbara Attard

Patsy Bigelow
from Janette Sherman, M.D.

Brenda Bradley
from Jody and Bill Bradley

Tory Brady
from Pamela Reaves, Ph.D.,
and Catherine Lee

Breast Cancer Action
from Bridget Galvin

Breast Cancer Action's Tenth Anniversary
from Marjorie Gelb and Mark Aaronson

Barbara Brenner
from Jenifer Sally Daynes and Romeo
Kassarjian
from Milton Estes
from Ann Hood
from Jane Kahn and Michael Bien
from Donna Korones and Ronnie Gilbert
from Vera Purcell
from Frances Strauss

Barbara Brenner and Susie Lampert
from Irma D. Herrera and Mark D. Levine

Suzanne Benton Bria
from Tracey Lynn Brown
and Allison C. Smith

Diane Carr
from Regina Gabrielle

Marilyn Charles
from Marci B. Seville
from Lisa Riordan-Seville
from Ruth and Leon Seville

Carol Eppolito
from Cynthia Burnes

Sandy Esperanza
from Laura Fenamore

Shari Hanis
from Mary Swan

Phyllis Hoffman
from Margot Smith Chmel
and Valentine Chmel

Mary Margaret Hough
from Ellen Shapiro and Meriel Lindley

Sherrie Kelley
from Rita and Ernest Tibbles

Karen Jo Kooman
from Marci B. Seville
from Lisa Riordan-Seville
from Ruth and Leon Seville

Brenda Kyne
from Regina Gabrielle

**The marriage of Valerie Lambert
and Sampson Reed**
from Lori Leigh Gielegem

Debra Mayo
from Sharon and Eugene Sullivan

Dr. Myrene McAninch
from Joanne Hilferty

Mary McCann
from Annette Schutz, James Bacchi
and ArtHaus

Jennifer Miles
from Noel and Christopher Abbott
from Noel Adams
from Margaret Babbott
from Ann Bower and Pat Simon
from Donna Brorby
from Amy Brown and Lisa White
from Stephanie Clarke
from Jim Emery and Charlie Spiegel
from Clarissa Flores
from Matthew Hagerty Fratus
and Jason Drew Heyman
from M. Ellen Haller, M.D., and Joanne Engel
from Kathy Haas and Eileen Santos
from Ruth Herring and Pam Peniston
from Claudia Hull
from Kevin James and Thomas Reilly
from Suzanne E. Johnson, M.D.,
and Deborah L. Stubbs
from Annie and Louis LaMotte, III
from Ursula G. and Thomas J. LaMotte
from Susan L. Marcus and Amie Miller
from Joe Margulies
from Carol Pederson
from Jennifer Pizer and Doreena Wong
from Kenneth and Fusako Reed
from Beverly Scott and Courtney
from Cameron Soroko
and John Jeming Soroko
from Barbara Stafford
from Willard Steane
from Karen Strauss and Ruth Borenstein
from Mort Weisberg
from Lauren Westreich
from Jill Wheatley

Dolores Moorehead
from Regina Gabrielle

Rachel Morello-Frosch
from Kathryn Ruiz

Our mothers for Mothers' Day
from Mary V. Hughes and Joe Simitian

R. Neary
from Joan Patten

Tanya Neiman
from Ann Hood
from Marci B. Seville
from Lisa Riordan-Seville
from Ruth and Leon Seville

Ilene Nelson
from Marcia Berenter and Janice Campbell

Melba Ortiz
from Leonard Altabet Worthy Eyes, Ltd.

Debra Oto-Kent
from Sarah Kuh

Dorothy Reed-Sleeper
from Ruth and Ray Sleeper

Margrit Robertson
from Maggie Crosby and David Robertson

Ali Roth
from Claudia Cappio

Agnes Russell
from Mary Saxon Taubman

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from Sandra Zook-Fischler

Brenda Solorzano
from an anonymous donor

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from Linda G. Marks

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from Elizabeth Leader

Susan Stone
from Ann Hood

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from Sylvia Teng

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and Harvey Wallender
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Nina Torcoletti
from Sally Emeson

Gwen Williams
from Darlene Minato-Buxton

Jane Zones
from Jane Kahn and Michael Bien

Donations in Memory

BCA gratefully acknowledges donations made in memory of the following individuals between April 18 and July 9, 2000.

Pat Anesi

from Lauri E. Fried-Lee
and Donald T. Lee

Loren Ausing

from Marianne and Alan Ausing

Ruth Barrett

from Beverly A. Burch

Lori Beckerman

from Jane Kahn and Michael Bien

Former Chief Justice Rose Bird

from Mary Friebe
from Susan and Robert Weisberg

Phyllis H. Blodgett

from Eleanor and Melanie Jechort

Brenda Bradley

from Leslie Murphy of W. Bradley
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from Patricia Filip and Nancy Lamb
from Gertrude P. Garvey
from Virginia and Robert Lamb
from Duane Little and Family
from Elwyn Little and Family
from Elwood and Mary Little
from Robert Little and Family
from Reverend and Mrs. Jim Little
from Margaret B. Polk
from Joyce and James Riggs

Emily Bridges

from Elizabeth Reidel

Reba Gilpin Canzano

from Tovia and William Freedman

Susan Claymon

from Nancy Brenner
from Ruth Joffe, Ph.D.
from Collette Sell and Donald A. Kline
from Katie Silberman
from Maida Taylor-Kelly, M.D.

Frank Cunningham

from Kathleen OiConnor Abrams
from Joan M. Cody
from Sandy and Steve Klein
from Kinuko B. Oiye
from Charlene M. Thomas

Francis Donish

from Ruth and Murry Fischer

Peggy Dye

from Felice Wells

Raymond Eisenstark

from Ellen Leopold

Barbara J. Freitas

from Eleanor Mendez

Adele Friedman

from Marcel Hawiger and Edith Friedman

John and Mary Galindo

from an anonymous donor

Lois Hock

from Mary Margretta Love and Tim
Meehan

Sharon Hock

from Mary Margretta Love and Tim
Meehan

Karen Hopfinger

from Ilissa and Stuart Sigman

Penny Jester

from Cynthia Duncan

Wendy Johnson

from Eleanor and Melanie Jechort

Johnnie Kline

from Mary and Doug Harmon

Bonnie Lang

from Elizabeth J. and Mike C. Buckley
from Sharon Flanigan
from Paul Kenney and Dede Steinfeld
from Susanne E. Lea and Russell Bruno
from Mary Jean Mitchell and Michael
Askenazer
from Suzanne Murphy and Bruce
Downing
from Linda Propert
from Audrey A. Smith

Ben Ludwig

from Maxeen and Bill Claymon

Alicia Madocks

from Jill Gallagher and Alicia Hasper

Bulletx Marasigan

from Regina Gabrielle

Sharon McDonald

from Jill Gallagher and Alicia Hasper

William Meyers

from Maxeen and Bill Claymon

Alma Borenstein Ohly

from Barbara and Joseph Blumenthal

Diane Kathryn Olson

from Janet Olson and Dale Martin Olson

Michael Sacks, M.D.

from Mary Jane Massie, M.D.

Shai Secrest

from Christine E. Nelson

Emma Shapiro

from Ellen Shapiro and Meriel Lindley
from Marilyn Ann Juncker

The Honorable Frank Shaw

from Alice J. Wolfson

Wendy Shaw

from Julie Rose Cowan and Neil Good

Kathy Sheets

from Patricia and Jerry Holt

Lucy Sherak

from Leslie and John DiGirolamo
from Ken Fischer
from Ruth and Murry Fischer
from Gladys and Bud Sherak

Patricia Sibley

from Ruth and Murry Fischer

Aunt Fran Smagacz

from Susan Tobin and Judy Spitzer

Chris Solomon and Jean Blanchard Solomon

from Susanna Van Leuven

Judy Steinmitz

from Jane Sprague Zones and Stacey Zones

Doña Treanor Tunnell

from Judith Cotham
from Merrill Clarke and Robert W. Hunn
from Collette Sell and Donald A. Kline

Velia Warner

from William Ash

BCA Wish List

Do you have a portable color TV or TV/VCR combo that you can donate to BCA? We are a private, nonprofit 501(c)3 organization, and your donation is tax-deductible. Please call our office at 415/243-9301. Thank you!

BREAST CANCER ACTION

55 New Montgomery
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California 94105

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*There are more than 2 million women
living with breast cancer in the U.S.
STOP THE EPIDEMIC!*

Resources

San Francisco Bay Area:

Bay Area Breast Cancer Network, San Jose
408/261-1425

Charlotte Maxwell Complementary Clinic
(free massage/other therapies for low-income
women with cancer)
510/601-7660

Community Breast Health Project, Palo Alto
650/326-6686

Marin Breast Cancer Watch
415/256-9011

Project Open Hand
415/447-2300 or **510/596-8200**

The Wellness Community, Walnut Creek
925/933-0107

Women's Cancer Resource Center, Berkeley
510/548-9272

State of California:

Breast Cancer Early Detection
(free screening for low-income women over 40)
800/511-2300

California Women's Law Center
888/774-5200

U.S. Government:

Information on breast cancer/clinical trials
sponsored by the National Cancer Institute
800/4 CANCER
(800/422-6237)

Up-to-date information on many
cancers, delivered via fax
CANCERFAX:
301/402-5874

Information on adverse reactions to
drug therapy
800/FDA-1088
(800/332-1088)

National Support/Health Groups:

National Y-ME (referrals to local chapters)
800/221-2141

National Women's Health Network
202/347-1140

National Asian Women's Health Organization
415/989-9747

National Latina Health Organization
510/534-1362

National Lymphedema Network
800/541-3259

Additional Resources:

For Young People
Vital Options, Studio City, CA
818/508-5657 or **818/508-5080**

Second Opinion
Regional Cancer Foundation (free)
415/775-9956

Medical Complaints in California
Medical Board of California

800/633-2322
Dept. of Corporations
HMO Complaint Line
800/400-0815

Pain Management Information
Mt. Zion Hospital, San Francisco
415/885-7246

Tell Washington
White House Hotline
202/456-1111
House & Senate Main Switchboard
202/224-3121

For Help on the Final Journey
Hospice Education
800/331-1620