The Status of the Intraductal Approach to Breast Cancer: Status Report to the Pioneering Community

By M. Ellen Mahoney, MD, Breast Medicine Specialist, HCBHP Community Advisory Board Member

Introduction by: Rose Gale-Zoellick, HCBHP Executive Director:

It was an evening in May 2008, Dr. Susan Love, the author of “Dr. Susan Love’s Breast Book”, presented “Breast Cancer and Beyond” at HSU’s Van Duzer Theater to launch a local research study about breast cancer prevention. HCBHP staff participated in the study’s Data Safety Monitoring Committee. Research takes time, and since then the study has been completed. Last fall, the results were published. We asked Dr. Mahoney to update us on the results of the study.

Clarification of the internal anatomy of the female breast has come to human knowledge late. In fact, if you look at most textbooks of breast disease and breast surgery, the word “anatomy” rarely shows up in the index. Sir Astley Cooper (1768-1841) was the first historical figure to attempt to delineate the anatomy of the breast and to discuss benign breast conditions. His 1840 book on breast anatomy, while otherwise a landmark effort, famously stated his opinion that the breast consisted of 15-25 ducts, an opinion which was unchallenged until the 1930s, but even after that very little attention was paid to anatomy. It just wasn’t considered important or relevant, it was too difficult to figure out, and the view of the breast as a homogeneous lump of tissue persists even to this day. There is now plenty of evidence that we are more like other mammals than not, and that the number of ducts is seven plus or minus two.

Dr. Susan Love set this issue to rest, starting out by going to the offices of the La Leche League and counting the number of white dots of milk at the end of the nipple in nursing mothers. This was followed by a study where MRI contrast was instilled into each of the duct openings separately, showing that this number of ducts accounted for the whole volume. This is a fact that was crucial in bringing understanding to the treatment of both benign and malignant conditions. The duct is a closed system, and breast cancer is a disease of the lining cells of one “sick duct”. The ducts are as completely separate as they are on your dog and cat. In humans, the ducts are gathered into one skin envelope, but inside they may intertwine but they do not interconnect, remaining physically separate from each other as on other mammals. This too is a relatively new concept in our thinking about the breast.

Our next change in concept involved looking at what changes cause these lining cells to change from regulators of fluid and electrolytes into the breast fluid to cells capable of digesting their way out of the duct wall. The step before breast cancer, Ductal Carcinoma In Situ, DCIS, was named before it was understood, and we have been unsuccessful in getting its name changed to take out the “carcinoma”. This need to rename this disease comes from new understanding that it does not mean that it is only a matter of time until these malignant-looking cells inside the ducts digest their way out to become real cancer. Continued Page 2
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In fact, only about 30% (14-53% in various studies) of ducts with these cells will ever take that last step. We can’t tell which ones will stay well-behaved, and which will ultimately become breast cancer, but if we could selectively remove or reset the lining cells from these closed systems we knew that no one could ever get breast cancer. These are the target cells for whatever causes breast cancer. If we can remove the target cells (a concept we called “chemical mastectomy”), there would be no disease resulting, just as I don’t worry about getting prostate cancer, and my husband doesn’t worry about getting ovarian cancer. This removal of tissues at risk is an accepted concept in cancer surgery: we remove thyroid glands from people with a genetic predisposition to thyroid cancer, and colons from people with severe ulcerative colitis to prevent colon cancer, to name just two. It works! And it renders moot the whole issue of causation which is so complex and expensive to sort out.

The first step in getting to that goal is to prove that we can use the duct as the delivery system to bring the right chemical to the surface of these lining cells, comfortably and safely. The next step will be getting the right drug to destroy or reset them. The second step is the more complex one, and it will take time to figure it out. We have thought about turmeric, tamoxifen, and other substances, but for our Humboldt study we chose Doxil (doxorubicin in a liposome) since we hoped that we would be able to quickly see the effect of the drug on the cells, to show that this idea works with minimal toxicity in just six weeks. We planned to have 30 volunteers with DCIS in one of their ducts in our study, with a couple of them as controls, to prove that drugs delivered this way affected the lining cells in a helpful way. Dr. Sara Sukumar at Johns Hopkins University did the preliminary rodent work in animals with extraordinary risks of breast cancer, and showed that it worked very well, with a large number of different drugs, but we were the first to try it in human women. Our first volunteer was a Eureka woman planning on a mastectomy, but we were the first to try it in human women. Our first volunteer was a Eureka woman planning on a mastectomy, who volunteered to have the treatment six weeks ahead of her surgery. It is a rare event in science these days to be able to say that we had no idea what would happen when we injected Doxil into one of her ducts, but all that happened was that she was recorded in new breast cancer textbooks as the first woman ever to experience this treatment. Dr. Love later did a study in China where carboplatin or Doxil was instilled into 5-8 ducts of women awaiting mastectomy, and they too showed that the process was safe and effective.

We were funded by the California Breast Cancer Research Program, and the study began, with Kelley Devlin-Lake, RN, as our study nurse. Ultimately thirteen women were enrolled and the measurements were histology, MRI and fluid proteins, before and after treatment. A group at Johns Hopkins University in Baltimore also began a study similar to ours. As both groups were working with women, however, Dr. Sukumar’s lab was continuing her work in rodents with other substances under a variety of conditions, none of which were similar to the conditions our women faced (like recent pregnancy). They questioned the use of Doxil as the best substance for risk reduction because it did not work as predicted in a particular strain of recently-pregnant mice. This left us with a short-lived dilemma: should we stop the study now and switch to other substances which were not controversial, or do we continue our study since our women had none of the characteristics of the mice who did not have the helpful results? The Data Safety Monitoring Committee met and discussed all of these points and the decision was unanimous: to the extent that there was any newly-discovered controversy about the drug we were using at all, we would not subject our volunteers to it. I was tasked with staying in touch with the women in the study, all of whom continue to be healthy and free of disease. Only one patient, later discovered to be BRCA positive in her 70s, had later bilateral breast cancer. This was judged not related to the Doxil, and she has done very well with treatment.

I recently got an update from Dr. Love, and she is planning to hold another symposium, and to continue the research. Now that both of us are over 65, we are also arranging to pass the baton of intraductal treatment to a new group to continue clinical work along with the group at Johns Hopkins University. There is a group at Harvard which looks extremely promising. Meanwhile the results derived from the tissue of the Humboldt County women who participated were also interesting and promising, and they were accepted for publication in Clinical Breast Cancer and published earlier this year. This continues to be a unique, new and practical research approach that we are sure will pay off big one year.

Because DCIS is a pre-cancerous condition with tough treatment decisions, this breast cancer prevention research study was a tremendous earning opportunity for our community and staff. Many thanks to Dr. Mahoney for providing an update on this study. ~ Rose

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Client Roundtable Provides Feedback
In March, a group of clients representing the diverse services at HCBHP got together with Executive Director, Rose Gale-Zoellick, and Warmliner, Chris Angell, to discuss what is going well and what could be improved. We thought you would like to see a few of the comments:

- There is immense compassion from volunteers, staff and other women here.
- People don’t realize that HCBHP is here for women with gynecologic cancer.
- I found that when you go to the doctor everything is clinical. HCBHP is different, it is the opposite of the clinical experience… the caring, personal side, more about me as a person and less about me as a patient. As patients we don’t always understand the clinical aspects, but we do understand our feelings. Contact with HCBHP provided a soft spot to land, Warmliners help me cope with my feelings, not just the medical side of things.
- GYN support group provides a sense of community. We are all in this together. We are like a family. I wasn’t expecting it, but there’s a lot of laughter in our group. I love that. Cancer can be crazy.
- I live in Fortuna and drove the distance to come to Arcata for support group. I had a Warmliner and felt like I was part of “something”. I missed the Arcata support groups because it conflicted with my treatment schedule. Now the Fortuna Support Group is great for me.
- I felt empowered – I understood what was going on. I felt armed with information, so I could ask questions or even challenge my doctor.
- I am not a support group person, I never went to support group. I had a Warmliner and loved the human contact. I appreciated her checking up on me to make sure I understood and she looked up information for me, always asking if I had everything I needed.
- Not enough people know what valuable support is available at HCBHP.

Resources for Mammograms, Pap Tests & Other Women's Health Exams
Women without insurance or with high patient costs and who may meet income guidelines can call HCBHP to learn more about the following programs:

CDP - Every Woman Counts: All local hospitals and many doctors’ offices/clinics participate.

Family PACT: All local hospitals and many doctors’ offices/clinics participate.

Mad River Hospital’s Free Mammography grant from National Breast Cancer Foundation.

Warmliners - The Heart of the Project
By Mary Meengs, MD, Client Services Director

Warmliner - It's a funny word, one most of us never heard before getting involved with the Humboldt Community Breast Health Project. We’ve heard of hotlines, where you can get information and support, but that term connotes a one-time contact, often at a time of crisis. Breast Cancer Connections in Palo Alto, the inspiration for HCBHP, refers to its phone volunteers as Helpliners. Other organizations use the term Navigator. As far as I know, “Warmliner” is unique to us. Our Warmliner volunteers are at the core of our service and identity. The role can be rewarding, challenging, and heartbreaking.

If you have walked into the Project during our drop-in hours, you were probably greeted by a Warmliner, sitting in the front room at a desk with a phone and folders. And if you’ve called us, most likely a Warmliner answered the phone. You may see her as a cheerful receptionist, but she is much more than that. When the phone rings or the door opens, she is prepared to meet someone who might have a worrisome problem or a terrifying new diagnosis. She knows that person may need a quick piece of information, or a long talk, a cup of tea, and a hug. The Warmliner will try to get that person whatever they need at that moment - information on how to get a mammogram paid for, a binder for her medical records, tips on getting through radiation - and will offer an ongoing relationship that involves periodic phone calls. With the client’s agreement, the Warmliner will check in from time to time to see if that biopsy got scheduled and if the results are back, or to see how chemo is going, or to listen to someone’s challenges with their loved ones. This relationship, which serves as an invitation to step a little more deeply into the Project, is what makes our Warmliners so completely different than a typical hotline volunteer.

The Warmliner position at the Breast Health Project is based on the Wounded Healer model, in which those who have experienced cancer, either personally or through caring for another, are in a unique position to further their own healing through the support of others. They can offer compassionate listening as well as specific advice and information. They serve as a constant reminder of an important aspect of healthy survivorship: we heal through service and bearing witness to others. We are forever grateful to their dedication and huge hearts!

A Special Gift for the Future
HCBHP has a fund at Humboldt Area Foundation, which makes it easy to leave a legacy gift to support the Project’s work in the future. If you have already included HCBHP in your estate plans, insurance policies or other planned giving, thank you, and please let us know so we can include your name in this special circle of supporters.

To learn more, contact Rose Gale-Zoellick at 707-825-8345 or Chris Witt at HAF, 707-442-2993 ext. 302
Spotlight on
Eel River Valley Outreach Center
By Rose Gale-Zoellick, Executive Director

There is now more support for people in the Eel River Valley and Southern Humboldt as they face breast or gynecologic cancer concerns. The Eel River Valley Outreach Center recently got a boost in volunteer support. Three new volunteers, whom are either cancer survivors or people with health care experience, joined the cadre of volunteer support. These volunteers are Jo Anne Center, Sonya Houseworth, and Francine Patterson. They join the three pioneering volunteers who founded the Center last August, Pat Cowan, Wanda Rigby and Gay Miller. All of the volunteers are looking forward to meeting folks seeking support and information on their cancer journey.

Additional support came from The McLean Foundation who awarded about $5,000 to HCBHP’s fledgling Eel River Valley Outreach Center to get phone and fax lines installed, promote the new center and get items that will make the Center even more private and comfortable for clients.

HCBHP’s Eel River Valley Outreach Center is co-located at the office of Visiting Angels at 1719 Main Street. We are thankful to Visiting Angels for donating this shared space. The volunteers are now staffing “drop in” hours at the ERV Outreach Center every Tuesday from 5:00-6:00 p.m. and every Thursday from 11:00 a.m. - 1:00 p.m.

The monthly support groups continue on the first Tuesday of each month from 6:00 - 7:30 p.m. For more information, please call 707-825-8345.

Quarter Craze
April 29th at 6:00 p.m.
Fortuna River Lodge,
1800 Riverwalk Drive, Fortuna

It’s crazy and fun! Come early to preview dozens of items that could be yours for a bid of one to three quarters. Local direct sales businesses bring fantastic items to auction and they will have their sale tables open for business at 6:00 p.m. Tickets are $5 at the door and include one Bidding Paddle. Up to two additional Bidding Paddles per person can be purchased for $3 each or $5 for two. Reserved seating is available for your group of friends by calling 707-616-3616.

Bring lots of quarters!

RN Breast Health Navigation
By Kelley Devlin-Lake, RN, BSN, OCN

Late last summer, I was hired as the RN Breast Health Navigator, thanks to a grant from the National Breast Cancer Foundation. My experience in local health care and with public health grants helped, as I needed to “hit the ground running” to reach out to women to help them access breast health exams and mammograms. In this role, I am the “point person” for the community health education team at HCBHP. Helping women navigate the health care system and overcome barriers to accessing it, is a privilege. When a woman is diagnosed with breast cancer, I am able to introduce her to the expertise of our organization’s professional staff, compassionate Warmline support and information, variety of support groups, medical visit preparation service, and many other resources.

I was recently asked to describe “a day in a life” of a breast health navigator. Some of the activities in which I have been involved the last six months include:

- Contacting women who have requested help with getting a mammogram, or dealing with a breast health concern,
- Meeting with stakeholders in Latina and Native American communities, faith communities, veteran and homeless advocates,
- Posting fliers, in local Laundromats, about women’s health screenings and low-cost or free options for mammograms,
- Conducting presentations to a wide variety of groups; I felt deeply honored to be included in a special event and presentation for women veterans,
- Tabling at health fairs and other community events,
- Providing serial weekly educational material to HCBHP Facebook page: “You are So Busted! 10 Excuses ‘Busted’ About Mammograms”.

If you are part of a group that would like a special presentation about women’s health and mammograms, please give me a call at 707-825-8345 x-135.

33rd Annual Atalanta’s Victory Run & Walk
An all women event!

This year the run/walk will take place on Mother’s Day, Sunday May 11 at 10 a.m. There will be a 2-mile run & walk or a 8K run & walk.

Proceeds from the event will be shared with Humboldt Community Breast Health Project and local running teams.

Sign up now! Online registration at - www.6rrc.com
Thanks to our Volunteers

We are Forever Grateful to Our Contributors

Thank you to over 850 individuals and businesses who generously donated since August. Space allows a partial listing of foundation, business and event supporters.

- All 65 Sales for Survivors participating businesses
- All Fall Concert sponsors & volunteers
- Andree Wagner Peace Trust
- Arcata Artisan's Cooperative for Arts! Arcata partnership
- Baroni Design
- Bear River Band of the Rohnerville Rancheria
- Bi-Coast Communication - Radio Group
- Blue Lake Casino & Hotel
- Buddy’s Towing & Auto Center
- Cypress Grove Chevre
- Donors and participants in the Bidding for Good On-Line Auction
- Emerald City Laundry
- Eureka High School EAST Lab Program
- Eureka Television Group
- Evans Mechanical
- Guiamar Hiegert Consulting
- Sunny Brae and Hensels Ace Hardware Stores
- HSU Women's Basketball, Volleyball & Football
- Humboldt Area Foundation
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- Humboldt Patient Resource Center
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- Marla Joy & All the Zumbathon sponsors & instructors
- McLean Foundation
- Miabo Family Foundation
- Mikki Moves Real Estate
- Miller Farms Nursery
- National Breast Cancer Foundation
- Patricia D. and William B. Smullin Foundation
- Phyllis Helligas’ 90th Birthday
- Punt, Pass & Pink participating High Schools
- Rebecca Stauffer’s Art Show
- Redwood Curtain Brewery
- Redwood River Resort
- Richard & Emily Levin Foundation
- Robert Goodman Winery
- Roy’s Club
- Safeway Foundation
- See’s Community Fund
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- St. Joseph Health
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- Women of the Moose
- Zane Junior High School

To receive a copy of our 2013 Annual Report with a complete listing of contributors, please contact us at (707) 825-8345 or view the program and fiscal reports at www.hcbhp.org

Other Ways to Support our Services

- Baroni’s Breast Cancer Education Jewelry - baronidesigns.com
- Hold a fundraising event
- Contribute your volunteer skills
Humboldt Community Breast Health Project
987 8th Street
(Corner of 8th & J)
Arcata, CA 95521
(707) 825-8345
(707) 825-8384 FAX

Office Hours
Mon-Fri 9 a.m. - 2 p.m.
After hours by appointment

Email: info@hcbhp.org
Website: www.hcbhp.org

Support Groups
Meetings held at the Project Office, 987 8th St., Arcata, unless otherwise noted. Meeting times may change. Call 825-8345 to confirm or to add your name to the reminder call list.

Arcata Breast Cancer Support Group  
2nd & 4th Thursdays of the Month, 4:30 -6:00 p.m.

Gynecologic Cancer Support Group  
2nd & 4th Tuesdays of the Month, 3:00-4:30 p.m.

Young Women's Breast Cancer Support Group  
1st & 3rd Tuesdays of the Month, 6:00-7:30 p.m.

Advanced Group  
For those living with Stage 4 Disease Every Monday, 11:30 a.m.-1:00 p.m.

Amazon Writers, a Peer-Led Group  
2nd & 4th Wednesdays of the Month, 3:00-5:00 p.m.

Fortuna Breast Cancer Support Group  
Visiting Angels Office, 1719 Main Street (near Shotz Coffee)  
1st Tuesday of the Month, 6:00-7:30 p.m.

Special Thanks to these Sponsors for Underwriting this Newsletter