



Call of the Amazons

Humboldt Community Breast Health Project
supporting women with breast or gynecologic cancer concerns

Volume 9, Issue 3

GYN Girls- Gynecologic Cancer Support Group



GYN girls Karen, Anne, Eddie, Sar, Ann-Marie and Jody

Recently I visited the Gyn Girls support group which is facilitated by Rebecca Zettler, NP. I was drawn into the room by the hearty laughter that I recognized from my own time in the group, which three other gynecologic cancer clients and I started almost five years ago.

My sisters in that group taught me about hope, humor, facing death, and living deeply and well with a life threatening disease.

Gynecologic cancers are tricky. The symptoms are often subtle and easily confused with those of digestive disorders. They occur less frequently than breast cancer, less research has been done, and there are fewer treatment options. Abdominal surgery and pelvic radiation can affect a woman's health, reproductive capacity, self-image and sexuality in ways that are different from breast cancer. There are no gynecologic oncologists in our area. To receive appropriate surgery and treatment consultation, women with suspected or confirmed gynecologic cancers travel out of the county to a cancer center.

Here are experiences of some of today's Gyn Girls in their own words.
-Carolyn Lehman

NEWLYDIAGNOSED

This is my first week at the Project. I had a lot of hesitation about coming here because I was having a hard time acknowledging my cancer. I was concerned about whether the Project would offer a positive environment. I wanted to call first, but just couldn't bring myself to do it.

When I walked in the door, a woman came to meet me immediately. She welcomed me and asked what she could do for me. Then she walked me through the building, showing me information pamphlets, the library and the informal meeting place in the kitchen, which is a comfortable place to sit and talk. I was introduced to Rebecca who went more into depth. She gave me a wonderful bag full of gifts and information to help me through chemo. This was perfect for me—comfortable, homelike, very embracing.

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Gynecologic Cancer Awareness by Julie Ohnemus, MD

September is Gynecologic Cancer Awareness Month. It's the perfect time to share facts about this group of cancers and give voice to some of the 78,000 women diagnosed each year in the United States. Although 28,000 women die from gynecologic cancers every year, there are now over 1 million gyn cancer survivors.

Johanna's Law: The Gynecologic Cancer Education and Awareness Act was signed into law in 2007. This legislation funded the Center for Disease Control's *Inside Knowledge* campaign which began to educate women and medical providers about gynecologic cancers:

- There are six main types of gynecologic cancer affecting a woman's reproductive organs: cervical, ovarian, uterine, vulvar, vaginal and fallopian tube cancer, as well as a number of related rare cancers.
- When gyn cancers are found early, treatment is most effective.
- Gyn cancers have warning signs, so pay attention to your body, and learn what is normal for you.
- If you notice unexplained changes that persist see a doctor, and don't hesitate to seek second opinions.
- Get Pap tests regularly to screen for cervical cancer.
- Get the HPV vaccine if you are 11–26 years old.
- If you are diagnosed with or have a suspicion of a gyn cancer, the CDC recommends that you see a gynecologic oncologist—a doctor trained to treat cancers of a woman's reproductive system.
- We now know that when initial surgery is performed by a gynecologic oncologist the risk of

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From the President & the Director

As this edition of the newsletter goes to press, staff and volunteers at the Project are very busy preparing for our Fall Awareness Campaigns and all the activities that go with them.

September is National Gynecologic Cancer Awareness Month. We will be getting the word out about prevention and early detection of women's reproductive cancers in partnership with local media. Since early detection is key to the best possible outcome, learning about these cancers is critically important for all women—and for those who care about them. In this issue you will find the latest recommendations on a wide variety of these cancers. Also in this issue are personal stories written by members of our gynecologic cancer support group which speak to the experiences of women coping with cancer, especially in rural areas like our own.

In October, National Breast Cancer Awareness Month, we are once again coordinating the very successful Free Mammogram Drawing with area mammography providers and the local chapter of the American Cancer Society. We are also excited about the research that Drs. Susan Love and Ellen Mahoney are conducting here in Humboldt County, research that could change the way early breast cancer is treated, and may even lead to the prevention of breast cancer.

For more on gynecologic and breast cancers, visit our website, www.hcbhp.org. Also on our website you will find more creative writing from the Amazon Writers support group. This healing-through-the-arts program is led by staff member Carolyn Ortenburger and poet/volunteer Kay Thornton-Fitts.

Sales for Survivors has become an annual partnership with local businesses. Please support and thank the local businesses that in turn help keep the Breast Health Project healthy! See the enclosed flyer or our website for details.

The highpoint of the Fall season is, of course, our gala October Concert. This year we are moving to the Arkley Center to accommodate the growing numbers of our supporters and friends who turn out for this heart-warming event. Please join us Saturday, October 18th, for a wonderful evening of music, laughter, tasty foods and local wines.

As always, we deeply appreciate all of you, our readers and friends. Our community depends on us to be here for women and their families in time of need. In these economically challenging times we depend on your generosity to keep us going. Thank you for your support.

Carolyn Lehman
President, Board of Directors

SueAnn Armstrong
Interim Executive Director

The Humboldt Community Breast Health Project

is a community resource of support and education for those facing a breast health concern or a diagnosis of breast or gynecologic cancer. We are a client-centered, grass roots organization with services provided by breast cancer survivors and their support persons. We promote healthy survivorship through education, healing support and hope, enabling each person to become their own best medical advocate. We support and challenge our community to address breast health concerns responsibly and holistically. As survivors we heal through service and by bearing witness to others.

OFFICE HOURS:
Monday - Friday, 9 a.m. - 2 p.m.
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receive future newsletters - or would like to
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newsletters, please call or email
info@hcbhp.org.



Dr. Susan Love and Dr. Ellen Mahoney

Free Mammogram Drawings

Drawings for free mammograms from Garberville to Crescent City will once again be coordinated by HCBHP and the American Cancer Society. This is a time to focus attention on the value of mammograms for early detection of breast cancer, and also an opportunity for women to receive information about financial assistance for screening.

Last year 37 mammograms were given away by the hospitals and the radiologists. All women who are at least 40 years of age are eligible. Call the ACS at 442-1436, ext. 3. Spanish speakers may call HCBHP at 825-8345, ext 135. **Entries will be accepted from October 1st until noon October 30th.**

Watch for details during Breast Cancer Awareness Month – and tell a friend!

Breast Cancer 2008 and Beyond

Internationally known breast health experts Dr. Susan Love and Dr. Ellen Mahoney held an audience of over 400 people spellbound in the Van Duzer Theater on June 19th. Speaking from a living room-like setting, the two research partners described their ground breaking study, taking place in Humboldt County, which has the potential to radically change the way early breast cancer is treated and perhaps eradicate breast cancer altogether.

The energy between the presenters and the audience, nearly half of whom were breast cancer survivors, was palpable. The question and answer period provided a time for digression into other aspects of breast health, including early detection and prevention. The two, who are long time friends, openly and humorously disagreed on some of the finer points.

The evening ended with a reception during which Dr. Love signed copies of Dr. Susan Love's Breast Book, the "bible" of breast health.

We thank Drs. Love and Mahoney for this hopeful and informative evening, and for the benefit dinner hosted by Dr. Mahoney that week. A DVD of the forum is available for a donation by request to 825-8345 ext. 220. Copies are available in the HCBHP library.

Intraductal Therapy of DCIS

A presurgery research study taking place in Humboldt County is looking for 30 women newly diagnosed with Ductal Carcinoma In Situ.

(707) 476-0690

Sponsored by The Dr. Susan Love Research Foundation & California Breast Cancer Research Program



Sales for Survivors

Get ready to shop and dine for a cause during September and October! Many local businesses donate ten percent or more of their sales on a specific day to support the services available at the Breast Health Project.

Please save the calendar insert and remember to thank the generous businesses where you shop and dine.

Thanks to CAB Volunteers

The Community Advisory Board, or CAB as it is affectionately known, is a committed group of skilled volunteers who offer advice and support. In May we held our annual meeting with members of the staff and Board of Directors.

Two focus groups brought insightful responses from CAB members. A group led by Sharon Nelson, RN, discussed client services. The second group led by Carolyn Lehman talked about stewardship and how to sustain the Project financially as we move away from start-up grants.

Would you be interested in working on the Community Advisory Board? Call Carolyn Lane, Board Liason, at 442-1020, or talk to SueAnn Armstrong at the Project office, 825-8345.



GYN Girls

Continued from page 1

My specific requests were to join a support group and to get information about my type of cancer. I was diagnosed when I was visiting Salem, Oregon. I went to the emergency room with what they thought was a blocked colon. They immediately thought colon cancer and I said, "No, I think it's the same cancer my mother has." I told them what markers to look for as I had just spent the last year supporting my mother through her chemo process, and they found it—primary peritoneal carcinoma, which is rare but has a lot in common with ovarian cancer. I flew directly to San Francisco and had a consultation with Dr. Powell. I'm having three rounds of chemotherapy up here before she does a second surgery.

I'm still working at looking my cancer in the eye. I know I need to face it and I want to do as many things as possible to keep myself strong physically, emotionally and spiritually.

What better place to go for support than to an organization where there are people who have been through the experience and information is available? The emphasis at the Project is on hope. When you are in my position that's exactly what you need.

.....
What better place to go for support than to an organization where there are people who have been through the experience and information is available?
.....

—Jody Hurlburt

ARURAL WOMAN

Location is a problem for someone like me, when it comes to getting treatment for gynecologic cancer.

I live in Willow Creek. When I was diagnosed with uterine cancer in July 2007, I made several trips to Fortuna and to Eureka for tests. I was told my surgery was to be in San Francisco at UCSF, where they have a gynecologic oncology department and I could see a specialist. My husband and I drove to UCSF for my initial visit and then two weeks later for my pre-op. Both times we drove down and back the same day—thirteen hours of driving—as we wanted to be home, safe and secure in our own bed.

When it was time for my surgery my husband, my 86 year old mother and I drove to Santa Rosa, checked into a motel and I began the cleansing procedure necessary prior to surgery. The next morning we drove to UCSF and were joined by my daughters, who live in Redding and Los Angeles. My family stayed in a motel while I was in the hospital.

The afternoon I was released I was told to go no farther than Santa Rosa, in case any problems developed. It was impossible to travel on Highway 101 last summer without encountering road construction. I remember all the "imperfections" the road had to offer! After ten days at home in Willow Creek, we drove to Santa Rosa and back for my follow up appointment.

There is a financial toll in terms of time, gas, motels, and meals to be paid when you live in a rural county. However, I do believe I received the very best of care at UCSF and from Dr. Bethan Powell. And that made it all worthwhile.

—Karen Madsen

FAMILY CANCER

My sister, Sylvia, was diagnosed with ovarian cancer in May 2006 and another sister, Nancy, in June 2006. We learned that we carried the BRCA gene. I wasn't having any symptoms, but I decided to have my uterus and ovaries taken out in March 2007. That's when I found out that I already had ovarian cancer. My youngest sister, Mary, also has the gene and has had breast cancer and a mastectomy. You go around thinking that life will always stay the same, then WHAM things start to change. In our case, radically.

While dealing with my sisters' cancers, I did a lot of research, but it just didn't feel like I had enough information. When I was diagnosed I was lucky that two friends directed me to the HCBHP. I talked with Rebecca Zettler. She listened to my story, suggested some reading materials and had someone do research for me.

I had to leave the area for a second surgery and for my chemo, which was rough going at times. Before I left Joy Hardin came by my house with a bag full of stuff to help me prepare mentally, including some funky socks to wear during surgery!!

When I was finished with chemo, I started attending the group meetings. At first, I was apprehensive but I found the group very supportive, a place where I can come to discuss whatever is bothering me. I also find comfort in the nice warm room where these wonderful women meet and share stories and information. Some days are hard, but some days are joyous. I've learned that it's okay to laugh.

I am so glad that we have this organization that is local and provides so many services to so many people. I have volunteered a bit but hope, as I get better, to give back what I can to help support and keep this organization going so that it will be here to help people like me in their time of need.

—Irene Blackburn

JOIN US!

One year ago, at the age of 76, I was diagnosed with fallopian tube cancer, stage 3. For a few moments my world stopped. Having always been a healthy and strong woman, I immediately put my trust in my doctors. They did a great job.

The cornerstone of my recovery was my family and friends. But I also felt a need for something just for myself, someone to talk with, a woman who was in the same boat I was. If it hadn't been for an article that I read in the newspaper last September, I wouldn't have known that the Breast Health Project had support services for women with gynecologic cancers.

One phone call to the Project allowed me to become involved with this wonderful group of ladies who like myself have suffered the ravages of cancer. Through humor, tears, and enlightened conversation, hope became real and recovery reachable. Participating in this support group helped me to focus on the broad meaning of life. To other women out there who don't know about us, I say, "Come join us!"

—Eddie Hannah



**NOTE FROM GYN GIRLS FACILITATOR
REBECCA ZETTLER:**

The new recommendation for all women with suspected or known gynecologic cancer to be seen by a gynecological oncologist (see page 1 article) comes with considerable ramifications for women in rural areas such as ours. The closest gynecologic oncologists are 300 miles away.

Women in the Gyn Girls support group have grappled with the implications, logistics, complications and cost of traveling far from home to get the care of specialists.

For those who have made the journey, and for those who did not, this continues to be an unfolding story. We look forward to a better understanding of how women with each type of gyn cancer could benefit from seeing a specialist, in order to help those with gyn cancers weigh the pros and cons in their decision to travel the distance.

2nd Opinions

Although many of us feel awkward raising the issue of second opinions with our medical providers, we all have the right to seek another perspective on our health situation, disease, pathology or treatment. It has been shown that when doctors are ill they often seek additional opinions.

When to consider a second opinion:

1. If you have been given no hope or don't feel heard
2. If something is "borderline" or gray about your case
3. If you live in a rural or isolated area
4. If you are a HMO member
5. If your doctor wants you in his/her clinical trial
6. If you have a rare cancer
7. If you have "cancer of unknown primary site"
8. If your pathology report doesn't give a definite diagnosis

Summarized from cancerguide.org/second_opinion.html. For a supplemental article go to www.hcbhp.org and click on Newsletter on the main menu.

Untitled Poem

I.

If I could be a flower,
I'd lift a brilliant face
towards the sun.
Gracefully swaying
aloft foliage lush with life.
Beauty to turn heads.
A scent to turn noses.
Bending them down
to thank me
with intoxicated faces.

II.

If I could be a flower,
I'd be a sunflower,
so bold and magnificent
because they bring smiles
to those who look upon them.
I'd be a snapdragon
because of their graceful beauty
and delicate scent.
I'd be a flower in a Himalaya
blackberry thicket so I could
bear sweet fruits.
I'd be an Iris
because they are beautiful
and remind me of grandma.
I'd be a lilac
because I could.
I'd be a rattlesnake plantain
or a trillium
so I could be one of the first
from the woods
to announce Spring.

I'd be a hollyhock
or a gladiola
to lure the hummingbirds.
I'd be a daffodil
so I could be the first
of the garden
to announce Spring.
I'd be a magnolia
because I want to prove
I can keep one alive.
I'd be a foxglove
because despite my beauty
it would be known not to
fool around with me.
I'd be a pansy
because they are dainty and charming.
I'd be a yarrow
so I'd be hardy.
I'd be an orchid
so I would live forever.
I'd be all of them
because I couldn't
decide on just one.

III.

If I could be a flower
I'd lift a brilliant face
towards the sun,
offering up all that
I was
all that I am.
to the world.

— Missy Gruen

For more poetry go to www.hcbhp.org and click on Amazon Writers on the main menu. The Amazon Writers support group meets twice a month. For more information call Carolyn Ortenburger, 825-8345 ext. 135, or email carolyno@hcbhp.org. No writing experience is necessary to participate.





Gyn Awareness

Continued from page 1

recurrence decreases and survival rates increase. The newest surgical techniques, using laparoscopic and nerve-sparing methods, improve quality of life in the short and long terms. The Society of Gynecologic Oncologists maintains a membership list of specialists (www.sgo.org).

The myth of **ovarian cancer** as “the silent killer” has been dispelled by studies showing that a majority of women (89 - 94%) with early stages of ovarian cancer **do report symptoms** at least a year prior to diagnosis. A first-ever consensus statement of symptoms was released in June 2007 by the Gynecologic Cancer Foundation, the Society of Gynecologic Oncologists, and the American Cancer Society.

If experienced daily for a few weeks, any one of these symptoms should prompt women to seek medical evaluation for possible ovarian cancer:

- Pelvic or abdominal pain
- Abdominal bloating
- Urinary urgency
- Urinary frequency
- Feeling full quickly while eating
- Difficulty eating

This consensus statement sets the standard for medical providers to include in their work-ups the possibility of an ovarian tumor – benign or malignant. Women should feel empowered and seek out this standard of care.

A brand new ovarian screening test for high risk women — women who have: a personal history of ovarian, breast or HNPCC type colon cancer; a family history of ovarian cancer, premenopausal or male breast cancer; a father with prostate cancer; or BRCA+ or genes for HNPCC. Labcorp’s test, Ovasure, is a 6 biomarker panel measuring proteins within ovarian cells. In blinded cohort studies Ovasure detected 91% of ovarian cancers at early stage, while ultrasound or CA125 detected 50%. It is also very specific, with 99.4% certainty in ruling out ovarian cancer. The recommendation is to proceed to an actual diagnostic work-up for women who test “positive” on 2 tests 3-4 weeks apart.

Other improvements in early detection of ovarian cancer may soon follow. Screening techniques in 39,000 asymptomatic women are being evaluated in the NCI Prostate, Lung, Colorectal and Ovarian Cancer Screening Trial (PLCO). After 4 years the interim report showed that the annual use of trans-vaginal ultrasound (TVU) found ovarian cancer at an earlier stage (77% at stage I/II) than those that annual CA125 blood tests found (90% stage at III/IV). This will be important to follow because standard guidelines currently suggest doing a TVS *only* when the CA125 is abnormal.

Cervical cancer is the only gyn cancer proven to be preventable. Since the introduction of the Pap test there has been a 75% decrease in cervical cancer. Pap tests are not perfect, however. It is the addition of HPV testing that can reduce the suffering and costs of treatment by earlier detection of precancerous cells. This genetic test looks for 13 strains of the human papilloma virus (the virus which causes 90% of cervical

cancers). Certain oncogenic types indicate a higher risk for cervical cancer. For Pap tests showing minor cellular abnormalities the HPV test can help guide the next steps in monitoring or treating. The American Cancer Society is recommending women over 30 have the HPV test with their Pap test. A recent study showed that if both tests are used together, 100% of the abnormal cells are detected. If both the Pap and HPV tests are negative, then you can wait for three years to have a repeat Pap.

HPV vaccination of 11 – 26 year old women and girls remains a strong recommendation. Gardasil blocked 99% of the HPV infections in the research study. This effectiveness dropped to 44% in women already exposed to HPV, so the vaccine does not eliminate the need for cervical screening. Other clinical trials underway include administering the HPV vaccine to males, and developing new second generation vaccines.

The HPV vaccine has also been shown to reduce the incidence of pre-cancerous cells leading to **vulvar cancer**. This type of cancer is on the rise in premenopausal women, and suggests a need for education on the vulvar/vaginal self exam (VSE). A good explanation with pictures and normal vs. abnormal findings can be found at <http://women.webmd.com/vaginal-self-examination-vse>. It is estimated that HPV vaccination could prevent two thirds of vulvar, vaginal, and perianal in-situ cancers in younger women. Other advances include recent studies showing equal survival for early vulvar cancers treated with less radical surgery than what has been standard for the last 20 years. Sentinel lymph node biopsy has also been proven safe and accurate for vulvar cancer and may decrease the problems with lower extremity lymphedema.

Uterine cancer is being studied by an international group of scientists in order to understand its biology, genetic and molecular basis, with the hope of individualized targeted treatment, risk reduction and prevention. One of the trials by the Gynecologic Oncology Group has been collecting samples of blood, urine & cancer tissue to form a tumor bank. It is about to begin its analysis.

The mechanisms of cancer are being studied by WHO’s International Agency for Cancer Research. A study released last year showed that deficiency in exposure to sunlight, specifically ultraviolet B (UVB), was one of the risk factors for endometrial cancer. Increased risk has also been shown for breast, ovarian, colon, and kidney cancers. UVB exposure results in production of vitamin D3. Because of our latitude and lack of sun for much of the year, **women in Humboldt County should get their vitamin D level measured**, specifically the vitamin D 25-hydroxy level, and if it is low take supplements.

As awareness of gynecologic cancers gains stride, activism is sure to follow. You go girls!!!

For additional articles including details about the four main gynecologic cancers go to www.hcbhp.org and click on Newsletter on the main menu.

We're forever grateful to our contributors

With deep gratitude and appreciation, we thank the following for contributions made from April 16 to July 15, 2008. Not included are all those who purchased raffle tickets. Please notify us of any errors.

Catherine W Andrews
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of Ann Seeman
Nancy & Thomas Sheen
— in memory of
Patrick Salt
Judy Sheldon
Loretta Sorensen
Rebecca Stauffer
Alex Stillman
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Janet Van Vliet
Catherine Walling
Jean Wichelman — in
memory of Ione Ellis
and Patrick Salt
Herbert C Wolfson
Rebecca Zettler & Kit
Mann

7th Annual Benefit Raffle

We've exceeded our goal of \$80,000 and couldn't have done it without the support of the many businesses and individuals who sold and purchased raffle tickets. We are grateful to each and every one of you, too many to name!

The winners of the 4 fabulous trips were:

**Karen Nessler, Emily Hobelmann,
Tami Matsumoto, and Ellen Clague**

A special thanks
to destination donors:

Chateau du Vertbosc, **Michel Allard**
Casita Salate, **Marcie & Mike Cavanagh**
North Country Farms, **Lee Roversi**
Tree Bear's Inn, **Mary Beth Wolford**

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Calendar of Programs & Events

Support Groups

Arcata Breast Cancer Support Group
1st & 3rd Thursdays of the month, 6:00-7:30 p.m.

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

Advanced Disease Support Group
For those living with Stage 4 disease
Mondays, 11:00 a.m.-1:00 p.m.

Guys' Night Support Group
For men whose partners have cancer
1st & 3rd Mondays of the month, 6:00-7:30 p.m.

Amazon Writers
For those interested in writing about their cancer journey
2nd & 4th Wednesdays of the month, 2:00-4:00 p.m.

*Meeting times may change.
Call (707) 825-8345 to confirm, or to add your name
to our support group reminder call list.*

All HCBHP services are provided free of charge.

Sales for Survivors

in September and October

*Please pull out the insert and support
businesses that are supporting HCBHP.*

Save the Dates!

Face to Face
September 4, 2008, 5:00-6:00 p.m. at HCBHP
Hosted by Michael Harmon, MD

November 6, 2008, 5:00-6:00 p.m. at HCBHP
Hosted by Ellen Mahoney, MD FACS

Healing Journeys
September 13-14, 2008
Memorial Auditorium, Sacramento, CA

October Concert and Elegant Reception

October 18, 2008 at 7:00 p.m. in Eureka
New Venue
The Arkley Center for the Performing Arts

"This Shining Night"
Heart-warming music presented by
Luther Cobb, piano
Brad Curtis, baritone
Elizabeth Harrington, soprano
Annette Gurnee Hull, accompanist

Tickets \$25
For information call 825-8345

Humboldt Community Breast Health Project

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Toll-free: (877) 422-4776
Fax: (707) 825-8384
www.hcbhp.org

Call (707) 825-8345 or e-mail info@hcbhp.org:

- To receive electronic newsletters
- To be added to our newsletter mailing list
- To be removed from our newsletter list

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*September — Gynecologic Cancer Awareness Month
October — Breast Cancer Awareness Month*