

**Inherited Risk for Breast and Gynecologic Cancer**

By Mary Meengs, MD, Medical Consultant

A few years ago, Angelina Jolie told the world she was going to have a bilateral mastectomy. She had tested positive for a genetic mutation in one of her BRCA genes, which she had inherited from her mother, who suffered from ovarian cancer. Jolie knew that this particular genetic mutation gave her a very high risk of developing breast and/or ovarian cancer over her lifetime. To further reduce her risk for breast or ovarian cancer, she subsequently had her ovaries and Fallopian tubes removed as well.

Publicity over her decisions increased the number of women seeking genetic testing and preventative surgeries. It's important to understand the risks and benefits of genetic testing as well as any interventions based on those results. Testing is typically expensive (though fairly easy, done on blood or saliva specimens), and the recommendations are complicated. Only 5 to 10% of cancers are strongly linked to inherited genetic mutations, although up to 15% of ovarian cancers are.

The most well-known genes involved in inherited cancer syndromes are BRCA 1 and 2. In the US, mutations occur in these genes in approximately 1 in 300 to 1 in 500 women. A harmful mutation in one of these genes increases the risk for breast, ovarian, and Fallopian tube cancer, as well as a few others. This mutation can be passed on by either a mother or a father, even if they themselves don't have cancer. There are many potential mutations which can have different effects, but overall, inheriting a significant BRCA mutation can increase a woman's risk of developing breast cancer from an average in our population of 12.3% to 45-65% or higher over her lifetime. A bilateral mastectomy done preventatively can lower that risk by up to 95%. Lifetime ovarian cancer risk can be as high as 50% with a BRCA mutation; removal of tubes and ovaries by age 50 can cut this by 90%, and also reduces the risk of developing breast cancer by 50%.

So, testing positive for a BRCA mutation, whether you've been diagnosed with cancer or not, provides an opportunity to potentially lower your own risks, as well as inform family members of their need to be tested. There are evidence-based criteria for who should be tested for any inherited cancer syndrome. For example, if you have been diagnosed with

Continued page 2

*Fall Benefit Concert*

*Music, Love and Light*

September 24, 2016

7:00 p.m. (doors open at 6:30)

Calvary Lutheran Church  
716 South Avenue, Eureka

Dr. Luther Cobb & Daniela Mineva on Piano  
Brad Curtis  
McKinleyville Community Choir  
Felicia Oldfather & chamber music group

\* Reception to follow \*

Tickets \$20 • Available at the door &  
BGHP 825-8345 & Wildberries Marketplace &  
Drs. Cobb & Mahoney Office 476-0688

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ovarian cancer at any age, or with breast cancer before age 50, with triple negative breast cancer before age 60, or with two different breast cancers, you should consider genetic screening. There are recommendations based on family history as well. The best strategy in any family is for the person diagnosed with cancer to be tested. If a mutation is discovered, family members can be checked for just that specific mutation. This is a fraction of the cost and interpretation of results much more straightforward. If testing of the cancer-affected family member is not possible, then a relative at risk can be tested, but interpreting results, especially for a negative test, is much less clear.

There are many other well known mutations and syndromes associated with both specific cancers and with clusters of different cancers. Lynch syndrome, for instance, is associated with approximately 3 to 5% of uterine cancers, the most common gynecologic malignancy. Lynch syndrome increases the risk for colon, pancreatic, brain, and other cancers as well as uterine.

Because decision making in genetic testing is so complicated, it is always recommended to see a genetic counselor. This professional can study your detailed family history and identify patterns that have been associated with known inherited mutations. This can lead to a recommendation for appropriate screening after you have discussed the pros and cons. Also, the genetics expert can advise you once the results are known. If a mutation is found, what are your risks, and are there risk-lowering steps you can take? Who else should be tested, and when? In families with a known BRCA mutation, children are advised to begin screening in their 20s. And if your tests are negative, is any future screening recommended? The field of genetic testing is rapidly evolving, with new mutations identified and additional testing strategies offered every month.

Continued on next column

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There are no genetic counselors located in our area currently, but fortunately, the St. Joseph Cancer Program has assembled a list of specialists in the Sacramento, Santa Rosa, and Bay Areas. Any of your cancer doctors, or we at the BGHP can share that information with you. And you can have testing locally; there are national guidelines for the most common syndromes that your doctor can follow, once you have made a decision together to proceed.

Remember, the goal of genetic screening for cancer risk is to become empowered with knowledge and choices. This information can help you make decisions about appropriate treatments if you've already been diagnosed with cancer, understand your future risks and steps you might take to lower those risks, and share that knowledge with your family. You should have a trusted expert advise you on testing and treatment decisions; every decision has potential risks and benefits. Feel free to contact us at the Breast & GYN Health Project, 707-825-8345, [www.bghp.org](http://www.bghp.org); we can talk things through with you and help you find any other resources you might need.



**From the Executive Director**

As we head into Fall 2016, the Breast and GYN Health Project staff and volunteers have been busy helping new clients. BGHP has seen a 38% increase in the number of people we have helped over the past four years. Although we never want anyone to hear the words "you have cancer", we are glad that BGHP is here to assist people in our community when they would like support.

The volunteers and staff at the Project are also looking forward to next year as we make plans for BGHP's 20th anniversary. We invite interested community members to contact me if you would like to get involved or if you would like to do a special educational event in your community.

As we approach the 20th anniversary year, we would love feedback from supporters and from those who have been assisted by BGHP staff or volunteers. How were you helped by the support and/or information you received? Is there something else you would like to see BGHP doing? As a supporter who may not have received services, how do you think we are doing?

Always feel free to contact me at 707-825-8345 x-110 or at [rosegz@hcbhp.org](mailto:rosegz@hcbhp.org). Your involvement makes support and information available for everyone in our community.

With gratitude,  
Rose Gale-Zoellick



## Rural Breast Cancer Survival Study Pilot Study Results

By Brenda Elvine-Kreis, MA, RBCSS Co-Principal Investigator, and BGHP Client Services Coordinator

Findings from the Rural Breast Cancer Survival Study (RBCSS) are now available. A California Breast Cancer Research Program grant was awarded in 2014 to the California Center for Rural Policy (CCRP) at Humboldt State University and the Breast and GYN Health Project (BGHP) to investigate differences between breast cancer death rates in Humboldt County and the rest of state, and factors associated with higher death rates from breast cancer in Humboldt County over the past 20 years. Specific findings of the RBCSS are available at [www.rbcss.org](http://www.rbcss.org).

Here are a few of the more interesting findings:

- 1) We were relieved to learn that the breast cancer death rate in Humboldt County is not as alarming as we initially feared. The impetus for this study was data from the California Cancer Registry (CCR) showing that Humboldt County has had one of the highest death rates from breast cancer in the state for over 20 years. The RBCSS enabled us to examine this data more thoroughly. Between 1990 – 2010, the average death rate from breast cancer (per 100,000 women) was 26 in Humboldt County compared to 23 in the rest of California. (There are only about 65,000 women in Humboldt County.) Although it is true that we have one of the highest rates, it is only *slightly* higher.
- 2) We were limited in our ability to examine all the factors that may contribute to breast cancer deaths (i.e insurance status, distance to care, etc.) due to missing data in the CCR database. Of the factors we were able to analyze, it was not surprising that age (>64yrs), stage at diagnosis (late stage), and tumor grade (grade 3) were related to a higher risk of dying from breast cancer in Humboldt County. What was interesting, though, was that unmarried women had poorer survival compared to their married counterparts. A recent study <http://onlinelibrary.wiley.com/doi/10.1002/cncr.29885/full> reported that the higher risk of death among unmarried cancer patients was more likely due to social support rather than economic advantages. This is something we can address because support for those with a breast or gynecologic cancer is readily available the Breast and GYN Health Project.



Co-Principal Investigators:  
Terry Uyeke, CCRP, Director of Evaluation and Community Services, and Brenda Elvine-Kreis, BGHP Client Services Coordinator.

Photo Courtesy of the Times Standard.

Continued - Rural Breast Cancer Survival Study

- 3) Contrary to popular belief, Humboldt County has a *lower* rate of women diagnosed at late stage compared to the rest of the state. This is good news, as it suggests that women in Humboldt County are being screened for breast cancer in a timely manner, allowing us catch breast cancers early, when they are most likely to be treated successfully.
- 4) Finally, for quite some time there has been community-wide concern that there are Hot Spots or Cancer Clusters of increased cancer rates in certain areas. Concerns center around exposures to potentially carcinogenic environmental toxins, ranging from water quality issues, to nuclear plant radiation exposure, to pulp mill pollution. Although the RBCSS was not designed to investigate this specifically, we did analyze for differences in survival rates between the five Medical Study Service Areas of the county, and did NOT find statistically significant differences, possibly due to the small populations in the five areas.

If you are interested in learning more about postmenopausal breast cancer risk factors there is a great interactive model on the California Breast Cancer Research Program's website <http://www.cbcrp.org/research-topics/causal-model.html>. This model allows the user to 'explore' the strength of the evidence and interrelationships between many risk factors.

### Drop-In BGHP Cancer Support Services in Your Community

#### FORTUNA

Drop-In Outreach Site  
Tuesdays 3:00-6:00 pm  
1719 Main St., Fortuna  
(Office of Visiting Angels)  
726-7919

#### GARBERVILLE

Drop-In Outreach Site  
Wednesdays 1:00-3:00 pm  
464 Maple Lane, Garberville  
(Heart of the Redwoods Hospice)  
943-9786

Breast Cancer Support Group  
1st Tuesday of each month  
6:00 – 7:30pm  
[www.bghp.org](http://www.bghp.org)

For more information:  
call BGHP, in Arcata  
(707) 825-8345

1.877.411.3662  
Toll Free



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**CAR Donations**

Are you interested in donating your vehicle?

Consider donating it to  
*Breast and GYN Health Project*  
It's hassle-free and your generosity is appreciated.  
Call Amanda at BGHP, for more information.

**Resources for Free Mammograms, Pap Tests & Women's Health Exams**

Women without insurance or with high patient costs and who may meet income guidelines can call BGHP to learn more about the following programs:

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

**Family PACT:** Many doctors' offices and clinics participate.

**Mad River Hospital's Free Mammography** grant from the National Breast Cancer Foundation.



Two Humboldt County health organizations are fortunate to receive grant funding from the National Breast Cancer Foundation (NBCF) in Frisco, Texas. These funds directly help women in Humboldt County.

The Breast and GYN Health Project's Breast Health Navigator, Madelin Amir, NP, is completely funded by the NBCF. Part of Madelin's job is to reach out to help women throughout the community who might need assistance getting women's health care, breast cancer early detection, diagnosis and treatment. The other part of her job is to help women navigate the health care system for these services. If you know a woman who might need extra support, please call Madelin at BGHP.

Mad River Community Hospital also partners with the NBCF to offer Humboldt County women who are income-eligible, underinsured or uninsured access to no-cost screening and diagnostic mammograms as well as breast ultrasound.

For more information about these services, please call us at the Breast and GYN Health Project. 707-825-8345.



Thank you to Safeway Foundation for the grant for outreach and client services! Thank you Safeway customers for contributing at the register in May 2016!



BGHP is a registered charity for Amazon Smile. Amazon donates 0.5% of the price of your eligible AmazonSmile purchases to BGHP.

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**Upcoming Events**

**City of Eureka Parks & Recreation  
Party in Pink Zumbathon  
Adorni Center - Eureka**

**October 8th from 5:30 - 7:30 pm**  
Michael Whiteley & several local instructors entertain, exercise and earn funds to benefit BGHP. Fabulous raffle.



**Zumbathon  
Bayside Grange  
October 30, 12 to 2 pm**

Registration - \$10 - \$15 sliding scale suggested donation.

Come early to register & check out the raffle. Two hours of high energy music & fun exercise with Marla Joy and ten other local instructors. Contact BGHP for more information.



When you shop at any of the Ray's Food Place stores throughout Humboldt County in October, please "Round Up" to support BGHP! Thank you Ray's Food Place & Customers!!

**Buddy's Auto Center**

The Pink Tow Truck is on the road raising funds, with \$5 from each tow donated to benefit BGHP. Thank you to supporters who added names to the truck. Buddy's Auto Center's phone #: 707-822-2615 or 530-629-2424



**BiddingForGood  
On-line Auction**

November 8 through 13  
Find good deals & support BGHP without leaving your home!

Check out [www.biddingforgood.com/BGHP](http://www.biddingforgood.com/BGHP)

For more information contact Amanda at [amandan@hcbhp.org](mailto:amandan@hcbhp.org)



**Your Legacy Gift will Provide  
Hope for the Future**

BGHP has a fund at Humboldt Area Foundation, which makes it easy to leave a legacy gift. Your investment in healing, compassionate support and hope will make a difference for cancer patients in the future. If you have already included BGHP in your estate plans, insurance policies, retirement plans or other planned giving, thank you!

To learn more, contact Rose Gale-Zoellick at 707-825-8345 or Chris Witt at HAF, 707-442-2993 ext. 302

## Thanks to our Volunteers and Supporters



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Thank you to all the  
volunteers! Thank you  
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& contribute in so many ways!



**Sign up for our monthly  
Project eNews**

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- Email [volunteer@hcbhp.org](mailto:volunteer@hcbhp.org) and we will add you to our Project e-News mailing list.



### Other Ways to Support our Services

- Call us about volunteering
- Buy a library book, see wishlist in eNews
- Hold a fundraising event
- Contribute your professional or special skills

## We are Forever Grateful to Our Contributors

*Thank you to over 1,530 individuals and businesses who generously donated since March. Space allows a partial listing of foundation, business and event supporters.*

- American Association of University Women
- Andree Wagner Peace Trust
- Arcata Artisan's Cooperative for Arts! Arcata partnership
- Arcata Exchange for hosting vacation raffle drawing and wine pour
- Bayside Grange for Zumbathon sponsorship
- Baroni Design for the special "Cancer Awareness" Jewelry Line
- Bear River Band of the Rohnerville Rancheria
- BiCoastal Media radio stations
- Heidi Bourne for the Mindfulness Meditation Classes
- Buddy's Auto Center's Pink Tow Truck in Arcata and Willow Creek
- California Breast Cancer Research Program
- California Cancer Crushers for choosing BGHP as a beneficiary of the "Wings for a Cure" event
- California Center for Rural Policy
- Cindy Hardin & Fortuna Quarter Craze fans for a successful event
- City of Eureka for Zumbathon at Adorni Center
- Cypress Grove Chevre
- Dae's Jewelry Sales & donations of earrings to clients
- Fall Concert sponsors and volunteers
- Ferndale's Old Steeple and Jeff DeMark for wine pour opportunity
- Financial Resource Center for grant support
- Hanger Clinic for donated breast forms and bras
- Hops in Humboldt
- Humboldt Herbals for "I love me" Tea for ChemoKits
- Humboldt Redwood Company for grant support
- Humboldt Unitarian Universalist Fellowship
- Kalos Salon for support with wigs for clients
- KHSU for media support
- KHSU Listeners and McLean Foundation for matching donation support
- KHUM & Lost Coast Communications
- KIEM TV - News Channel 3
- Richard & Emily Levin Foundation
- McLean Foundation for Eel River Valley Site support
- Mikki Moves Real Estate for Non-Profit Collaboration
- National Breast Cancer Foundation
- Nicole Nada for the Integrative Wellness Fund
- Patricia D. and William B. Smullin Foundation
- Redwood Capital Bank for Fortuna Site support
- Redwood River Resort
- Redwood Sports Car Club and British Car Club for choosing BGHP as the beneficiary of the Two-Seater Car Show
- Safeway Foundation for grant funding for breast cancer early detection and patient navigation
- Sales for Survivors business participants
- Six Rivers Running Club for eight years of support by including BGHP as a beneficiary of the "35th Atlanta Victory Walk & Run for Women"
- Soroptimists International of Arcata
- Soroptimists International of Eureka and Humboldt Bay
- Times Standard for the large media support in October
- Trinidad Lion's Club
- Vacation Raffle destination donors, sponsors, ticket buyers and incredible volunteers
- Visiting Angels for donating use of the Fortuna Office Space

*Thank you!*

To receive a copy of our 2015 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](http://www.hcbhp.org)



987 8th Street  
(Corner of 8th & J)  
Arcata, CA 95521

(707) 825-8345  
(707) 825-8384

Email: [info@hcbhp.org](mailto:info@hcbhp.org)  
Website: [www.bghp.org](http://www.bghp.org)

Client Services Drop-in Hours  
Mon-Fri, 9 am - 2 pm  
After hours by appointment

Administration: 9 am - 5 pm

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Garberville Wednesdays 1 - 3 pm



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**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 pm

**Gynecologic Cancer Support Group**

2nd & 4th Tuesdays of the Month, 3:00-4:30 pm

**Young Women's Support Group**

Call for information.

**Lymphoma Group at BGHP**

1st Tuesday, 4:00-5:30 pm

**Advanced Disease Group**

For those living with Stage IV Disease.  
Every Monday, 1:00-2:30 pm

**Amazon Writers**

Explore creative writing as a path to healing.  
(Call to be put on waiting list for next series.)

**Fortuna Breast Cancer Support Group**

Visiting Angels Office, 1719 Main Street (near Shotz Coffee)  
1st Tuesday of the Month, 6:00-7:30 pm

***Special Thanks to these Sponsors for Underwriting this Newsletter***



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