



Lymphedema - A Toll of Treatment

By Mary Meengs, MD, Medical Consultant

Some side effects of cancer treatment are not too obvious to the casual observer, like fatigue, peripheral neuropathy, or sexual difficulties. But at the doctor’s waiting room or in line at the pharmacy you may have spotted someone with one very puffy hand or arm, possibly wearing a tight elastic sleeve or glove. That’s lymphedema.

Our lymphatic system was not included in the illustrations of the human body most of us studied in school. Nonetheless, everyone has one and it performs several important functions. It can be considered a sort of sewer system that drains fluid just under the skin. Lymph is a clear, watery fluid that carries proteins and immune molecules around the body, in a network of channels that resembles the circulatory system. Lymph nodes are like filtering stations through which the fluid flows; they can “catch” cancer cells, bacteria, etc. They are typically soft and the size of a small bean; there are 600-700 lymph nodes in the body, clustered in critical regions like the head and neck, abdomen, and the “roots” of the extremities in the groin and armpits (axillae). You usually can’t feel a lymph node through the skin unless it is swollen and inflamed due to infection or cancer.

Primary lymphedema can be caused by a genetically determined abnormality in the structure of the lymphatic system. Here, I’m talking about secondary lymphedema, where the lymph drainage system and nodes are damaged by surgery, radiation, or infection, and no longer function properly. Lymphedema is characterized by progressive swelling and tissue thickening due to inflammation from this damage. In breast cancer patients, the swelling can be in the arm, hand, breast or trunk, on the same side of the body as the cancer.

In addition to swelling, lymphedema can cause achiness, heaviness, and fullness, or other odd sensations, and trouble in the fit of clothing and jewelry. Anyone with symptoms lasting more than 7 days should see their doctor, as treatment begun earlier can be more effective. In the early stages, the swelling can be reduced by elevation, but as the condition progresses, the tissues get tougher (fibrotic) and swelling can become permanent.

The risk of developing lymphedema if you’ve been treated for breast cancer is 6-20%; it is most likely to occur in the first several years after surgery and radiation, but the risk persists lifelong. Lymphedema can also occur following surgery and/or radiation for gynecologic cancers; the symptoms show up in the legs. The risk is reduced by removing as few lymph nodes as possible, and by having the smallest possible field of tissue radiated. Weight gain or infection after cancer treatment can also increase the risk of lymphedema.

Continued page 2 ...

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What can be done to reduce the risk? According to the National Lymphedema Network (www.lymphnet.org), preventive strategies can be organized into 3 areas. Skin care's main goal is to avoid trauma or injury and reduce the risk of infection, and includes:

- Keep area (ie, arm) warm and dry
- Apply moisturizer daily to prevent chapping/chafing of skin
- Attention to nail care; do not cut cuticles
- Protect exposed skin with sunscreen and insect repellent
- Use care with razors and avoid nicks and skin irritation
- If possible, avoid punctures such as injections and blood draws
- Wear gloves while doing activities that may cause skin injury (like gardening)
- If scratches/punctures occur, wash with soap & water, apply antibiotics, monitor closely
- If a rash, itching, redness, pain, increased skin temperature & swelling, fever, or flu-like symptoms occur, contact your physician immediately

Attention to activity and lifestyle involves gradually building up the duration and intensity of activity or exercise, resting frequently during activity, and monitoring the extremity during and after for changes in size, shape, texture, or sensations; it also means maintaining a healthy weight.

The third area of prevention is to avoid limb constriction. This means never having blood pressures taken on the arm at risk, wearing loose-fitting clothing and jewelry, and wearing a well-fitted bra.

If lymphedema develops in spite of all the above, seek treatment as soon as possible. You will want to see a physical therapist who has had specialized training in treating lymphedema, ideally a Certified Lymphedema Specialist. The Intensive Phase involves manual lymphatic drainage – performed by the therapist and taught to the patient – and special types of compressive bandaging. The therapist provides lots of education about skin care, movement and exercise.

Much of this information came from a recent webinar produced by Living Beyond Breast Cancer. You can access the entire archived presentation at www.lbbc.org; look in the event library under transcripts and recordings for 1/22/2015.



From the Executive Director - Rose Gale-Zoellick

As clients regularly remind me, we are so fortunate in this community to have dedicated volunteers and staff who are cancer survivors to help people facing breast and gynecologic cancer concerns in our community. I am grateful for their deep commitment and countless hours of service. There continue to be new ways we try to support our community and this newsletter allows us to share the news with you.

Lymphedema is a bigger issue than I had realized. I was recently surprised to learn that it affects not only breast cancer survivors, but people with gynecologic cancer and other conditions as well. Because it's such a common condition, I appreciate Dr. Mary Meengs' contribution about the topic for this newsletter.

I count on your continued support of our work and your participation in our grassroots organization. If you have questions, comments or want to get more involved in anything you read about in this newsletter, please get in touch with me at 707-825-8345 x-110 or rosegz@hchbp.org.



Welcome Lisa Petterson, RN, new Client Services Director

By Rose Gale-Zoellick, Executive Director

In mid-April, we welcome Lisa Petterson, RN, as our new Client Services Director. Lisa is a cancer survivor and former client who brings many years of experience in women's health to BGHP. She has also worked very closely supervising and training volunteers throughout her career. We are excited to have her joining our team.

"Having gone through a journey with cancer myself, I look forward to becoming part of an organization that provides support and advocacy to others trying to navigate through the medical and emotional world that a cancer diagnosis brings. The Breast and GYN Health Project has touched the lives of so many. I look forward to learning from and supporting the amazing clients, volunteers and staff that make up the current and future BGHP community," Lisa reflected.

Lisa, the Warmline volunteers, and our clients will continue to have the support of Mary Meengs, MD, and Julie Ohnemus, MD, as advising Medical Consultants; and Brenda Elvine-Kreis, as our part-time Client Services Coordinator. We were fortunate to receive grant funding from the Patricia D. and William B. Smullin Foundation to support Lisa coming aboard.



Rural Breast Cancer Survival Study

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

In our last newsletter (Fall, 2014) we announced a new grant that BGHP, in collaboration with the California Center for Rural Policy (CCRP) at HSU, was awarded by the California Breast Cancer Research Program (CBCRP). We have been busy with the start-up phase of this pilot study.

We wanted a user friendly name that the public would recognize, so we changed the name of the study from “Exploring Rural Disparities in Breast Cancer Mortality,” to the “Rural Breast Cancer Survival Study” (RBCSS). This study is the result of data from the California Cancer Registry showing that for the past 20 years Humboldt County has had one of the highest rates of death due to breast cancer (mortality rate) in California. In contrast, the number of women who develop breast cancer in Humboldt County (incidence rate) has actually been slightly *below* the state rate. This study is designed to explore factors that may be associated with decreased survival from breast cancer in Humboldt County.

Current grant activities at BGHP have included putting together a website where we will post announcements and updates www.rbcss.org. If you would like to be kept up-to-date as we move forward with the study, please access this website and sign up to be on RBCSS’s mailing list. (If you do not have internet access you are welcome to call me at 707-825-8345 to sign up.) We are now developing “Learning Exchanges” that will be open to all community members on topics related to breast cancer and the research data we will be using, as well as more about Community Based Participatory Research. These will also be made available via social media and other outlets. The findings from our data analyses will be shared via Community Forums in late 2015.

Stay tuned for announcements regarding the upcoming Learning Exchanges and Community Forums!



Courtesy of the Times Standard

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



Eel River Valley Outreach Center

BGHP’s Eel River Valley Outreach Center has shifted its hours to better support clients. The devoted volunteers welcome people to drop-in every Tuesday from 3:00-6:00 p.m. and the support group meets the first Tuesday of each month from 6:00-7:30 p.m. at 1719 Main Street, Fortuna (office of Visiting Angels). The volunteers are willing to set up appointments outside of these hours to meet with people facing a breast cancer scare or diagnosis, so please feel free to call the Arcata office at 707-825-8345 to request an appointment.

ASTRO Grant 2015



Check presentation photo at ASTRO Conference in San Francisco with ASTRO CEO, Laura Thevenot to Rose Gale-Zoellick, BGHP Executive Director and SJH Radiation Oncology Team, Sarah Williamson, Drs. Luh and Harmon, Radiation Oncologists, and Department Director, Curtis Prevost.

The American Society for Radiation Oncology (ASTRO) awarded the Breast and GYN Health Project their prestigious “Survivors Circle” Grant for direct patient care for patients undergoing radiation therapy. BGHP is using these funds to help patients who are currently in radiation therapy for cancer and need assistance with funds for transportation. These funds are only available through September 2015, or until the funds run out. If you know a local cancer patient who could use funds for transportation, please call us at (707) 825-8345.

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Call Beth, at BGHP, for more information.

A Special Gift For the Future



BGHP 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 BGHP (aka 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

405 ✓

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Support the California Breast Cancer Research Program using box 405 to donate on your CA State income tax form. Independently run by the University of California, CBCRP supports innovative research.

Privilege and Pleasure: In the Name of Service

By Kelley Devlin-Lake, RN, BSN, PHN

The phone call came mid-morning on a Monday. I took a few deep breaths and re-focused my attention to the person on the other end of the phone. I heard her say, “I have breast cancer, I am pretty certain of it, in spite of pathology pending...and I need your help.” Over the next several months we had many phone conversations and I accompanied her to a local surgeon for consultation after helping her identify her questions. Our phone calls touched on many aspects of the treatment(s) she was considering; retaining records for the medical binder she got from BGHP, post-surgery garments, time away from work and disability, self-care, making her home comfortable for after surgery, and asking for help during her recovery and recuperation.

Near the end of her treatment, she called one day and spoke with one of the staff: “I am so grateful for your services and for Kelley’s support and information; she has been there every step of the way, helping me to know what to expect with each visit to the doctor. She gave me just the right information each week during treatment.”

A consistent pleasure of my nursing career has been connecting with people in the name of service, no matter the setting or situation. In the role of Breast Health Navigator for BGHP, I have the opportunity to meet people in a multitude of venues: health fairs, community events and presentations, tabling at fund-raisers, *and* right here in our office. One of my co-workers at the Project has been heard to say, “this is my heart job!” It truly is that for me.

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 BGHP to learn more about the following programs:

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

Family PACT: Many doctors’ offices/clinics participate.

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



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

Just search for “Humboldt Community Breast Health Project” when prompted (*we have not updated our name yet.*) It’s easy! Visit: smile.amazon.com

Survivor Story

by Nancy Lee



Breast cancer was diagnosed with my routine annual mammogram. My surgeon described it as “the smallest cancer I’ve ever seen”. She and her office staff persuaded me to check in with BGHP and I was met there by a sensitive Warmliner, who delicately gathered my history and info, handed me a binder for my medical records and encouraged me, even before my surgery, to attend Support Group.

The Group was large that night, and my overwhelming impression was how ready they all were to laugh! Not that I expected somber solemnity, but the room seemed light-filled and comfortable, and the comments droll, the stories tinged with humor.

Two chairs away, a woman, clearly so ill she’d literally dragged herself out of bed, rather than miss it. Experiences were shared and the room rocked loudly and often with easy laughter. One such time drew a small smile from the frail woman. Suddenly, I realized what the Group represented to this woman. The Group is not just support; it is an emotional anchor for all of us in the same boat. It is a sanctuary where we can acknowledge our fears and even our miseries and find compassion and understanding from those who have “been there, done that”. It is Hope personified by our fellow survivors. The Project doesn’t function like most “businesses”. It doesn’t just click merrily along on its own steam. It is a group effort by few staff members, and a range of never-ending assistance needed from a whole host of volunteers — helping in so many ways, little or lavishly.

As for me? Lucky, lucky, lucky. And “so far, so good”. It is satisfying to be able to “give back” so that somebody else coming along can “get”. It is a peerless part of one’s own healing. Volunteering is one of the ways to make your own survival count for something.

Oh, and what of the very ill woman at the meeting that night? I saw her again at Group some months later: Upright and steady. Eyes, clear and sparkling. Color glowing, hair growing back. Yeah ... and laughing.

34rd 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 an 8K run & walk.

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

Sign up now! Online registration at - www.6rrc.com

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 Volunteer Coordinator/Resource Asst. - Beth Gaughan
 Breast Health Navigator - Kelley Devlin-Lake, RN, BSN, OCN
 GYN Cancer Support Group Facilitator-Rebecca Zettler, RN

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We are Forever Grateful to Our Contributors

Thank you to over 820 individuals and businesses who generously donated since August. Space allows a partial listing of foundation, business and event supporters.

- ASTRO - American Society for Radiation Oncology for the Survivorship Circle Grant to help with transportation for clients
- Andree Wagner Peace Trust
- Arcata Artisan's Cooperative for Arts! Arcata partnership
- Arcata Playhouse for "Jonna's Body, Please Hold" partnership
- Baroni Design for our special "Cancer Awareness" Jewelry Line
- Bear River Band of the Rohnerville Rancheria
- BiCoastal Media radio stations
- Bidding for Good On-Line Auction donors and participants
- Blue Lake Casino & Hotel
- Cindy Hardin & Fortuna Quarter Craze fans for a successful event
- Dalianes Travel, Diane Williams, and artists who contributed to "Support our Girls" March benefit at Arts Alive
- Dae's Jewelry Sales & donations of earrings to clients
- Denny Dorsett's Jin Shin Jyutsu benefit workshops
- Emerald City Laundry
- Eureka High School EAST Lab Program
- Eureka Television Group
- Fall Concert sponsors and volunteers
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- HumboldtMade and its members who donated to Bidding for Good
- Humboldt Dutch Brothers Coffee
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- Humboldt Unitarian Universalist Fellowship
- Kalos Salon for support with wigs for clients
- KHSU
- KHUM & Lost Coast Communications
- KIEM TV - News Channel 3
- Richard & Emily Levin Foundation
- Linden & Co - special day donated by all their professionals
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- National Breast Cancer Foundation
- North Coast Journal
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- Punt, Pass & Pink participating sponsors and high school football teams and cheerleaders - for 3 years
- Redwood Preparatory School fundraiser
- Safeway Foundation
- Sales for Survivors - all 65 business participants
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- Times Standard
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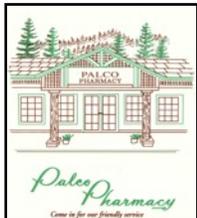


Support Groups

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.

<p><u>Arcata Breast Cancer Support Group</u> 2nd & 4th Thursdays of the Month, 4:30-6:00 p.m.</p> <p><u>Gynecologic Cancer Support Group</u> 2nd & 4th Tuesdays of the Month, 3:00-4:30 p.m.</p> <p><u>Young Women's Support Group</u> Call for information.</p> <p><u>Lymphoma Group</u> 1st Tuesday, 4:00-5:30 p.m.</p>	<p><u>Advanced Disease Group</u> For those living with Stage IV Disease. Every Monday, 1:00-2:30 p.m.</p> <p><u>Amazon Writers</u> Explore creative writing as a path to healing. (Call to be put on waiting list for next series.)</p> <p><u>Fortuna - Breast Cancer Group</u> Visiting Angels Office, 1719 Main Street (near Shotz Coffee) 1st Tuesday of the Month, 6:00-7:30 p.m.</p>
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