

Breast Cancer Coalition **BCCR**

VOICES OF THE Finger Lakes Region of Central & Western New York

PALSSM Mentor Training: Increasing the Number of Peer Mentors Across the Region -By Tracy Brown

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On a brisk Saturday morning in January, breast cancer survivors from Monroe and surrounding counties gathered to learn how to become compassionate and effective peer mentors at our annual PALSSM (Peer Advocates Lending Support) mentorship training in Rochester.

PALS is a unique program in which a breast cancer survivor, typically a newly-diagnosed person, is connected to another survivor from the same age group who received a similar diagnosis, surgery, treatment, and recovery plan. The mentor, who is further along in her cancer journey, can provide invaluable insight and kind support to their mentee. The Coalition can also connect newly diagnosed gynecologic cancer survivors to peer mentors with similar diagnoses.

This day of learning is led by Coalition staff – many of whom are survivors themselves – and a licensed therapist. During training, participants have the opportunity to engage in role playing; to learn more about local and regional resources; and to network with other survivors over lunch.

Increasing the number of active, regional PALS mentors is critical to widening our network of support across the region. While mentors often talk to their mentees by phone and through email, we would like to connect mentees to a PALS mentor living nearby so that they have the option of easily meeting in person if they choose to do so.

Regional survivors, we need YOU! Help us grow our network of trained peer mentors. Become a PALS mentor and empower others who are living in the aftermath of a breast cancer or gynecologic cancer diagnosis.



Local survivor Lee Cortese is joined by regional survivors Doreen Secor and Julie Carasone at PALS peer mentorship training



Regional survivors Barb Klube-Falso and Kim Riccio model active listening during role playing exercises

Continued on back cover

PALSSM Mentor Training continued

Would you like to learn more about PALS? Contact us! To request your volunteer PALS Mentor application, or to request a peer mentor for support following your diagnosis, please email Associate Program Director Pat Battaglia at pat@bccr.org. You can also call the Coalition at 585-473-8177 to speak with staff. ☺



Associate Program Director Pat Battaglia welcomes survivors to PALS peer mentorship training

A Q&A with Albion, NY Group Facilitator Carol Kistner



We caught up with Carol Kistner, facilitator of our Albion group, to learn more about the Coalition's first regional support / network group. Participants typically meet the first and third Wednesday of the month at the Hoag Library, from 5:30 – 7:00pm. Please contact the Coalition at 585-473-8177 to confirm the next meeting date and location prior to attending.

What is the purpose of the Albion group for survivors of breast or gynecologic cancers?

We offer participants the opportunity to share their stories among others who also journey with cancer. Participants agree that a compassionate listening presence is a precious gift.

Through discussion we can learn the vocabulary and technology of cancer treatment. But, more importantly, we model for one another the courage and resilience that engender a firm commitment to hope.

Who comes to the group for support?

Our group has welcomed individuals of various ages, of both genders, and with an array of diagnoses, treatment choices, outcomes, and experiences of survivorship. Some are newly diagnosed; some have been on their journey for a decade or more.

Why should someone who has received a diagnosis of breast cancer or gynecologic cancer come to a meeting?

If you long to learn and laugh, to share your strength as well as your vulnerability within a

knowing, safe community, to give and receive the healing love that resides within each of us, this group could be just what you need. Please join us!

To learn more about the Albion Support / Network Group, contact the Coalition at 585-473-8177 or email Tracy Brown at tracy@bccr.org.

Coming Up!

The Breast Cancer Coalition's Pink Ribbon Run & Walk

Sunday, May 14, 2017

Genesee Valley Park, Rochester NY



Questions? Call 585-473-8177 or email Cindy Dykes at cindy@bccr.org

For details and to register and fundraise online: www.BCCR.org

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Kathy Cunningham – sister, wife, mother, grandmother, retired computer programmer, and “blues traveler,” sat down with us to share her breast cancer journey that began on an ordinary morning in December.

It was a Saturday morning in December 2015. As Kathy Cunningham prepared to shower, she looked into the mirror and noticed something didn't look right. A mammogram the previous August followed by a clinical breast exam in September hadn't revealed any areas of concern, but now something was wrong with her right nipple. She shrugged it off in the moment, because there was nothing she could do on a weekend. On Monday, she called for an appointment.

Three separate mammography views revealed nothing suspicious. An ultrasound was performed, but with her dense breast tissue, still nothing showed. However, there was some sort of “shadowing.” The decision was made to move forward with a needle biopsy. At this point, Kathy was sure there was a problem. As she left, she asked the radiologist for her thoughts. The doctor answered, “I'm not optimistic.”

The following evening Kathy got the call: she had breast cancer. She was directed to schedule an MRI and find a surgeon. Two of her friends had just undergone breast surgery, and Kathy checked in with them to learn about their experiences. Afterward, eager to schedule her surgery, she made an appointment for the following week. The connection was made. Kathy and her husband John were comfortable with the surgeon. From the beginning, Kathy was certain of her decision to have a bilateral mastectomy. With the difficulty she'd encountered in finding the cancer in her right breast, she did not want to risk the same possible situation with her left. She opted out of reconstruction.

Between her mammography appointment and the meeting with her surgeon, Kathy had an MRI, which showed what appeared to be a 3.5cm tumor in her right breast. She felt the sooner she could get the surgery done and over with,

the better. In the end, her mastectomy was scheduled for December 28 at noon.

“I felt – and I think the surgeon felt – that we had caught it early enough,” Kathy said. “We knew there would be surgery, and then I would go on an aromatase inhibitor for five to ten years.” (Aromatase inhibitors are a class of drugs that reduce the risk of recurrence for postmenopausal women with early-stage hormone-receptor positive breast cancer.)

“I never even took a pain pill [right after the surgery]. I felt fantastic. By 5:00pm it was snowing and I sent everyone home but my sister Lynn.” At 6:00pm Kathy got out of bed and the two sisters played cards until 11:00pm. She went home the next day.

“My sister Peggy set-up a ‘meal train’ for me online. I wasn't comfortable with all the help, so I told them someone could bring me a meal every other day for just a couple of weeks,” Kathy admitted.

The “eye opener” came a week and a half after the surgery, when the surgeon called to share the pathology results.

The tumor was larger

than originally thought: it measured 8cm. Concerned, the surgeon told Kathy it was likely she would need more treatment than initially planned.

“Everything was in my favor, but the size of the tumor was not,” Kathy said. In January, her oncologist explained that due to the size, the recommendation was for six months of chemotherapy followed by five weeks of radiation.

Despite the change in treatment plans, Kathy feels that she had it easy. She was proactive in her treatment and when anti-nausea medications and steroids caused trouble during her chemotherapy, she made sure to report her experience back to her doctor so adjustments could be made. After her second treatment, she went back to work as an aide on a special needs school bus, finishing chemotherapy in June. She also did well during radiation,



Sisters, left to right: Luana Bailey, Kathy Cunningham, Toni Sue Estruch, Peggy Hamilton, and Lynn Copeland

saying that although the 45-minute drive to appointments wasn't ideal, fatigue was never much of a factor for her. Skin discomfort that arose a week after radiation treatments ended was easily treated with creams.

A few weeks later, Kathy noticed a feeling of tightening under her arm where a bra would normally press. There was a noticeable range of motion loss, too. Concerned about lymphedema, she contacted her radiation team. Kathy was given an option to see a therapist to be fitted for a lymphedema bra, but she learned that it was not lymphedema after all. The muscles and tissues were just tight.

Through Kathy's year of diagnosis, surgery, and treatment, there were moments of spiritual healing – specifically of the musical kind. “Do you know who Keb' Mo' is?” Kathy asked.

“There is definitely life after diagnosis.”

Kathy loves blues music, and Keb' Mo' is one of her favorite blues musicians. “I have been a big fan of his for years and have seen him in concert before in different places. He was just at the Lilac Festival.” The day after his Lilac Festival performance, he was scheduled to play at Turning Stone. Her devoted sister Lynn convinced Kathy to make the trip to Verona to see Keb' Mo' play once again. Once there, Lynn disappeared to the will call counter.

Kathy was surprised – and thrilled – to learn that Lynn had contacted Keb' Mo's people and explained that her sister had been dealing with breast cancer, was a huge fan, and asked if they could arrange a special face-to-face meeting between them. They said yes! Kathy would be allowed backstage to meet the talented musician.

It was wonderful! Keb' Mo' was friendly and Kathy explained how just that morning she had a chemo treatment for her breast cancer and tonight she was listening to him play at the concert. She shared how much she loved his music. Before they parted, Keb' Mo' and Kathy took off their hats, exposing their bald heads while Lynn took a picture of them. “It was a great night,” Kathy grinned.

Since her diagnosis and coming to the Coalition, Kathy has participated in regional Gentle Yoga classes and joined a Coalition committee. She is keen to get the word out about our programs and services to other survivors. She loves the regional evening educational seminars.

As we ended our conversation, we asked Kathy, “Where are you now?” It was three months after her last radiation treatment and she reported no real issues with the aromatase inhibitor. A chest scan was scheduled, followed by an appointment with her oncologist.

“You just need to get on with your life,” Kathy finished. “You can't go on thinking it's going to happen again. There is definitely life after diagnosis. Just know that you are going to come out on the other side. It's a major life change, but there can be positives.”



Kathy with husband John

What's Going On?

The Coalition brings free educational and supportive programming to select cities and towns across the region.

Do you want to know when we are holding an event or offering a program in your area?

Contact us and get on the list! Call Tracy Brown at 585-473-8177 or email her at tracy@bccr.org and request to be added to the regional notification list.

Breast cancer survivors and gynecologic cancer survivors: Interested in free Gentle Yoga?

The Coalition is currently offering classes in Dansville, Geneseo, and Geneva. Additional cities / towns are being considered for this special program in 2017.

Want to learn more about issues that are important to those who have received a diagnosis of breast or gynecologic cancer?

Our educational seminars are held throughout the region. Topics range from reducing the risks and managing the symptoms of lymphedema, to understanding the long-term effects of radiation.



Dr. Kevin Mudd presented at our Batavia educational seminar in March