

Breast Cancer Coalition

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



Pictured above: survivors Montha Chang and Laurie Miller volunteer together at the Coalition's outreach booth during the Canandaigua Art & Music Festival. Thank you, ladies!

We Have Places To Be in 2018!

We had just barely finished sweeping away the New Year's confetti before we reviewed our calendar for 2018. Wow – it's going to be a busy year!

While continuing to grow our regional programs – such as Gentle Yoga, Mindfulness & Meditation, and other supportive offerings – we also plan for those events where we engage in outreach. When the nicer weather comes to the region, so do opportunities for growing our community of survivors.

From volunteering at a booth at the Canandaigua Art & Music Festival (typically held during the second weekend in July), to helping deliver newsletters to offices located in the counties surrounding Monroe, the Coalition can always use an “extra pair of hands” to help us reach more people. Survivor-volunteers are the BEST volunteers. They often draw upon their own experience with breast or gynecologic cancer when volunteering at our outreach booth. It's a great place to meet new friends and talk about Coalition programs.

So, what do you say? Do you want to show your support of the Coalition's regional work by volunteering in the upcoming year? Great! Contact Tracy Brown directly at tracy@bccr.org or call 585-473-8177. We can't do it without you! ☺

*Now Welcoming Women
with Gynecologic Cancers*

BCCR.org/regional

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Save the Date:

Saturday,
Feb. 3, 2018



The next PALS_{SM} (Peer Advocates Lending Support) training has been scheduled for breast cancer and gynecologic cancer survivors who are ready to serve as mentors to those who are newly diagnosed. The training is free and lunch will be provided. Please contact Pat Battaglia, Associate Program Director, at 585-473-8177 or pat@bccr.org for more details and to receive a PALS_{SM} training application.



Dr. Elena Nedeia, a radiation oncologist from UR Medicine | Noyes Health, answers a question about radiation treatment posed by one of the attendees at our fall Dansville evening educational seminar.



Sylvia A. Ryndock – *a busy career woman, a wife, mom to a daughter and two sons, and blessed with a grandson. We sat down this past fall to talk about her journey after hearing the words, “you have breast cancer.”*

Sylvia was – and is – a healthy woman. Busy with her family and career, she has no time for illness. But in early winter 2013, Sylvia raised her right arm and noticed a lump on the inside of her right breast. (Years earlier, a pea-sized lump under her arm on the same side was found to be benign.) After showing her husband, Mark, she called her doctor. Sylvia was immediately scheduled for a mammogram, followed by an ultrasound. The lump appeared to be solid, and a biopsy was performed. Sylvia had a sense that the results were not going to be good.

On December 27, 2013, Sylvia received the news: she had breast cancer.

There’s never a good time to receive a cancer diagnosis and Sylvia’s experience was no different. She and Mark had recently decided to switch their health plan to one with a lower premium and a higher deductible. After all, they were “healthy people” and believed they would need their insurance only for routine appointments and screenings. Now, faced with Sylvia’s diagnosis, they suddenly needed to switch back to their original insurance. Mark took action and spoke to his employer. Fortunately, timing was on their side and they were able to keep their health plan.

The doctor who performed the biopsy referred Sylvia to a surgeon and she opted to have a lumpectomy. However, the pathology results revealed that the margins surrounding the tumor were not clear; it was uncertain whether all the cancer had been removed. She would need to schedule a second surgery. Sylvia remembers thinking, “I’m already small! There’s not much more to take!” She was also directed to talk to a medical oncologist.

During her appointment with the oncologist, Sylvia learned that his recommendation was for chemotherapy to begin right away. It was Monday and he wanted her to start treatment on Friday. Sylvia resisted. She was not “ready” for chemotherapy – she wanted to move forward with the next surgery. All along, she had believed chemotherapy would come later in her breast cancer journey. “In my mind, I just wasn’t prepared for chemo to begin!” she said.

The oncologist explained his concern: if Sylvia had the surgery and waited until she had recovered enough to start chemotherapy, too much time would be lost. He shared his observations with her surgeon, who advised her to follow her oncologist’s recommendation.

Sylvia accepted the situation and moved forward with treatment. Because she was also HER2/neu positive (meaning that Sylvia’s cancer overexpressed the HER2/neu protein, a growth factor in some breast cancers), she was prescribed the drug Herceptin along with her chemo regimen.

That Friday she received a “cocktail” of three chemotherapy drugs: Taxotere, Carboplatin, and Herceptin. This was followed by two Fridays of Herceptin only, and then the series began again with her Friday “cocktail.” For four and a half months, Sylvia was on this treatment cycle. Afterward, she continued with Herceptin alone for a year.

Sylvia reported she felt fine after her Friday “cocktail” treatments. Then a couple of days later, she would “feel it.” There was no pain, but also no energy. She took medication to prevent nausea, and never became sick as a result of chemo.

After the first treatment, Sylvia’s white blood cell count dropped and she needed to bring her numbers back up. She received shots to help with this and eventually took the responsibility of giving them to herself at home. When her white blood cell count became low, Sylvia limited outings to the store and church to reduce the risk of contracting something contagious. Sometimes she wore a medical mask when she needed to interact with the public.

When the conversation turned to chemotherapy and hair loss, Sylvia observed, “We as women really like our hair. We fuss over our hair. That’s the way we are! And I was okay, I guess, with losing my hair until the remaining ‘fuzz’ I had was cut off. I did get emotional and cried a little, but then I was okay.”

Sylvia kept her sense of humor – even when her wig blew off in a parking lot. “I was picking up my Mom from her home and as I was putting her in the car, the wig just blew off! I chased it across the parking lot, grabbed it, and threw it back on my head. When I looked around to see if anyone saw this, I noticed a lady sitting in her car laughing. It was funny to me, too! I got back in the car and drove off.”

It was summer when Sylvia went bald. At that point she felt no need for hats, wigs, or scarves and found the choice freeing. She would put on her make-up and go! One person, unaware of Sylvia’s treatment, asked if her baldness was a ‘fashion statement.’ Sylvia replied, “No, this is a chemo statement!”



Sylvia with her husband Mark

Save the Date!



The Annual Cindy L. Dertinger Advanced Breast Cancer Seminar: Tools for the Journey will be held on Friday, April 13, 2018 at the Memorial Art Gallery in Rochester's beautiful ArtWalk neighborhood.

**Seminar: 1:00-5:00pm,
Reception: 5:00-6:00pm**

The panel of speakers will include members of the region's medical community, as well as two survivors who are living with metastatic or stage IV breast cancer. A short reception follows the program.

Breast cancer survivors of all diagnoses, family members, friends, caregivers, and members of the medical community are welcome to attend. **RSVPs are required** so that we may plan appropriately. Please contact the Coalition for more information and to request to be added to our invitation list.

We hope you will be able to attend this or any of our other programs. Call the Coalition at 585-473-8177, or visit our website at www.bccr.org to learn more.

Sylvia's last day of chemo was also Mark's birthday. The couple celebrated together. "The treatment center gave me a stone to mark the day. I chose [the one marked] Peace." Although she originally thought she would have radiation, her treatment plan did not include it.

Because Sylvia's cancer had a significant risk of returning, she opted for a bilateral mastectomy with reconstruction in October of 2014. Sadly, her mother passed away from brain cancer a month prior. Upon waking after surgery, Sylvia became emotional about her mother's absence but her family was there to console her.

Sylvia's reconstruction involved tissue expanders and implants, and she laughs when remembering her experience. Having opted for a breast size just a bit bigger than her original one, her surgeon eventually "cut her off" from saline injections into her expanders, saying: no more! Permanent implants were inserted in spring 2015.

During the Q&A session at a Breast Cancer Coalition educational seminar, Sylvia inquired about one of her final reconstruction procedures. "I brought the subject up and invited other women to tell me about their experiences. I received a lot of ideas and now will be moving forward to finalize that part of my journey."



Sylvia shows spirit at the Coalition's 2015 Mother's Day walk/run event

***"Don't 'become' a cancer patient.
It's not who you are, it's what
you're going through."***

Sylvia had wonderful support throughout her experience – from her husband Mark; to her children, sisters, and brothers; to her church family. When asked how she is doing now, Sylvia replied, "I would say that I am well. After my surgery, I felt released! I was released from all that went along with my breast cancer journey. There was no longer 'delaying' my

life." Already a realtor, Sylvia acquired her broker's license and opened her own brokerage. "I am enjoying life to the fullest!"

She offered this advice for those who are just starting their breast cancer journey. "You can survive this. Don't allow it to redefine your life. Don't 'become' a cancer patient. It's not who you are, it's what you're going through. You might cry, feel sorry for yourself, and feel pitiful, but don't stay there! Get back up and fight." ♡

Cancer Services Programs by County

Free breast, cervical, and colorectal cancer screenings for women and men who have no insurance or are under-insured.

(Age restrictions apply.)

Allegany & Cattaraugus Counties

Call: 585-593-4839

Chautauqua County

Call: 1-800-506-9185

Erie County

Call: 716-858-7376

Genesee & Orleans Counties

Call: 585-344-5497

Livingston & Wyoming Counties

Call: 585-786-8890 or
1-800-588-8670

Monroe County

Call: 585-224-3070

Niagara County

Call: 716-278-4898

Ontario, Seneca, Wayne, & Yates Counties

Call: 315-462-0602

Steuben County

Call: 877-778-6857 or
607-324-8811

What's Going On?

The Coalition brings free educational and supportive programming to select cities and towns across the region. From evening educational seminars, to Gentle Yoga, to Mindfulness & Meditation classes, and more, the Coalition works to make programs available for our regional survivor community.

We're preparing our 2018 calendar and expanding our programming! Do you want to know when we are holding an event or offering a program near you? Then get on our list! Contact Tracy Brown, Regional Programs & Outreach Director, at 585-473-8177 or email her at tracy@bccr.org and ask to be put on the regional notification list.

Educational Information & Easy Exercises at Our Recent Geneva Seminar on Complementary Therapies



Margaret Newland, a Registered Yoga Teacher, discusses the benefits of yoga on the body at our Geneva evening educational seminar. Margaret is also the instructor for the Coalition's Gentle Yoga program in Geneva.



Certified Meditation & Mindfulness Teacher **Rick Lynch** describes the importance of breath before leading evening seminar attendees in a meditation exercise. Rick is also the instructor for the Coalition's Mindfulness & Meditation program held in Canandaigua.

Mary Conley Sarratori, MSAOM, L.Ac, an acupuncturist from The Springs Integrative Medicine & Spa, Clifton Springs, presents on how acupuncture can be included alongside and after treatment during our seminar on Complementary Therapies.

Meeting with Our NYS Elected Officials



Representatives from the Coalition traveled across the region this past fall to thank our elected officials who support our regional programs and outreach. Pictured here: Holly Anderson, Executive Director; NYS Senator Patrick M. Gallivan (District 59); Tracy Brown, Regional Programs & Outreach Director; and Carol Kistner, a member of the Coalition's Regional Community Outreach Committee.