

Regional Education & Supportive Programming
Why They Matter -By Tracy Brown

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Yoga instructor Kate Drake and her Dansville students celebrate their heart center

The Coalition set several regional goals for 2016, including a planful rollout of supportive and educational programming in targeted areas. After reviewing feedback from regional survivors and stakeholders, we began to strategically plot out what could be done in the short term (springtime), with an eye toward building a stronger network that would allow us to increase our regional offerings in fall 2016.

We began with evening educational seminars to the east and west of Rochester. Our first seminar, held in Geneva, focused on nutrition after breast cancer. In Batavia, we discussed the role of chemotherapy before and after breast surgery, and followed up with a new seminar on nutrition.

We headed south of Rochester to launch our first regional program, Gentle Yoga. The Dansville yoga pilot did so well that we've continued the program in 6-week sessions since then, enrolling new participants into every session. We also piloted a 4-week session of Gentle Yoga in Bath late last spring. These programs are important to our regional survivor community. For years, we have heard that survivors living outside of Monroe County "wish they had something like us" closer to home.

Continued inside



Dr. Nayana Ramdas Kamath speaking at the Batavia evening seminar in March

What Can Regional Breast Cancer Survivors Access Now? -By Tracy Brown

The Coalition offers free educational opportunities, networking events, and supportive programs for breast cancer survivors. Our programs are also open to gynecologic cancer survivors. While most events take place at our Rochester location, some programs can be modified to meet the needs of our regional survivors closer to home.

Evening Educational Seminars are held January through October at 7pm on the fourth Wednesday of the month at the Coalition in Rochester. We also hold Regional Evening Educational Seminars in select cities outside of Monroe County. Topics range from nutrition after breast cancer to treatment protocols. Contact us to be added to our regional mailing list.

Peer Advocates Lending Support (PALS_{SM}) is a unique mentorship program in which a newly-diagnosed individual is connected to a breast cancer survivor who is a trained peer mentor*, and whose diagnosis, treatment plan, and life situation are similar. PALS mentoring can be provided through one-on-one

meetings, over the phone, and by email. ***Become a Regional PALS Mentor!** Contact Pat Battaglia, Associate Program Director, at pat@bccr.org to request more information and a volunteer mentor application.

Cover story continued

The support we receive from regional community stakeholders shows us we are on the right track.

"The Coalition has become an excellent resource and support for breast cancer survivors in Genesee County," says Lisa Franclemont, Health Educator and Program Coordinator for the Genesee and Orleans Counties Cancer Services Program. "The local educational seminars provided by the Coalition for survivors are invaluable and fill a void in our region."

Fall 2016 finds us piloting yet another Gentle Yoga session, this time in Geneseo. Additionally, we've increased the number of evening educational seminars throughout the region, with topics ranging from breast density and breast cancer screening; to the long-term effects of chemotherapy; to managing lymphedema.

We're grateful for the support we've received from our regional communities of survivors, supporters, and stakeholders. We look forward to delivering even more regional programming opportunities as we grow our network.

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Survivor Spotlight continued

monthly injections to induce menopause. "I had chemo every three weeks. Mine didn't last that long, though," she added. "Only about three to four months." Radiation was not part of the protocol for Julie, and her treatment was finished.

When talking about getting through treatment and her recovery, Julie credits her mother the most. "My mom was the best person. I don't think I would have gotten through this without her. She took care of my daughters and my cat. Actually, she spoiled them," Julie grinned. "But my mom is always there for all of us - all of our family."

As our conversation came to a close, we asked her what she would say to someone who had just received a diagnosis of breast cancer. What would the Julie of today have said to herself, back when she first learned about her own diagnosis?

"It will be okay. You'll get through this. Just keep on plugging away." Julie paused. "I still do that. I try to live life to the fullest. Don't get sucked into drama. Be happy. And if you can't change whatever is bothering you, don't worry about it anymore."

Good advice, indeed! ☺

Save the Date! Young Survivor Soiree

November 4th at 6:00pm at our Rochester location.

RSVP required!

Call us at 585-473-8177 for more information.

Survivor Spotlight -By Tracy Brown



Julie Carasone – *The Coalition met young survivor and mom Julie Carasone at a breast cancer survivor round table hosted by New York State Senator Ranzenhofer in Batavia. She's full of energy, and possesses a practical, down-to-earth attitude. She's kindly agreed to share her story with us.*

After Julie Carasone's maternal aunt was diagnosed with breast cancer in December 2008 following a routine mammogram, she asked her daughter and all of her nieces – including Julie – to schedule their own mammograms to make sure they were healthy and cancer free.

Julie's cousins and sister were told that they were too young for mammography, but at 36 years old, Julie was considered to be "close enough" to 40, and was told to go ahead with the screening. The mammogram revealed that Julie's right breast was "full of micro-calcifications." The left breast had hardly any at all. The doctor told Julie he was concerned about one certain spot and wanted to take a biopsy.

By then, it was March 2009 and Julie's mother traveled from Virginia to help her daughter at home. The surgeon who performed the biopsy originally thought things "looked good," so Julie sent her mother back to Virginia. But at a follow-up appointment, her doctor delivered the news: Julie had cancer in her right breast.

Julie, always direct and honest, replied to her doctor, "Well, that just stinks."

Right away, Julie called her daughters' schools to let their teachers know she would be telling her children that night that she had breast cancer. Her girls were in third and ninth grades at the time and, worried about how they would feel, Julie wanted to inform the administration in case one of them needed to talk to a counselor.

That evening, her eldest daughter didn't take the news well. Somewhat angry, she disappeared to her bedroom. The next day, however, this same daughter called from school to let Julie know that she loved her. A member of the school's administration and a teacher – both touched in some way by breast cancer – had sat with the teen in the chapel to help her process her feelings about her mother's diagnosis.

Another phone call was made, this time to Julie's parents in Virginia. When Julie told them about her diagnosis, her father, a recently retired Army Colonel, instructed her to read exactly what it said in the biopsy results. "Then my dad

went into a fix-it mode," Julie remembers with a chuckle. "Within the hour, I get an email from my dad that was CC'ed to my brother, my sister, and all my relatives."

The email explained Julie's diagnosis, what she would be possibly going through, and stated that they would have more information about her treatment in the coming weeks. Julie added, "I'm reading his email and actually laughing, because that's my dad for you."

Julie's grandmother's best friend lived locally and decided to go Roswell Park Cancer Institute with Julie for the first full day of consultations. This family friend, Sharon, felt bad that Julie learned of her breast cancer by herself. She wanted to make sure Julie had someone



Julie with daughters Felicia (left) and Gabrielle (right).

by her side if things became overwhelming. Sharon was on hand to write everything down as Julie went through her appointments. A date was set for a mastectomy with reconstruction, and Julie called her mother with the information.

"I was very lucky," Julie said. "My dad was taking time off before he went back into the workforce as a civilian, and my mother wasn't working either. I think God knew I needed my parents." Julie explained that her family is true to their faith, and often look to God for guidance. "St. Peregrine is the patron saint of cancer," she told us. "My sister made me a 'chemo quilt' with all of our kids' favorite things included in the pattern, like a frog and military emblems. On each corner, there was a religious symbol. One had a cross, another had St. Peregrine's medal."

"My faith helped us through," Julie finished.

Six weeks after her surgery, Julie began chemotherapy. She also participated in a study at Roswell that included

Cover story continued

If survivors live too far away, they might not have the time to attend programs in Rochester—especially if they are still in the workforce or have family responsibilities. If they are in active treatment, driving to Rochester might not be practical. And traveling poses a financial challenge for many, particularly when medical expenses may be burdensome.

We find it meaningful when regional survivors affirm the importance of programming in their areas.

Kate Drake, RYT, leads the Coalition's Gentle Yoga classes for breast cancer survivors and gynecologic cancer survivors in Dansville. She also led the Gentle Yoga pilot session in Bath. As the Coalition explored the possibility of launching one of its Healing Arts programs regionally, Kate's name kept surfacing in survivor circles. Other community stakeholders were familiar with her as well.

"The Gentle Yoga program has built a common ground for survivors in our rural area. In class they find a place where they can relax and find a comforting bond where they share their experiences openly and without judgement," Kate told us.

Kathy Fierthaler, a breast cancer survivor, is in Kate's Dansville class. "I could really have used the companionship and knowledge of other women who were, or had been, in this situation when I was diagnosed. There was nothing available in this area,"

she shared. "The yoga program your organization is sponsoring in Dansville now has been wonderful for me and, I believe, for the other participants. It has been so very good to spend time and speak with women who have had to deal with this disease."

Our regional evening educational seminars introduce us to survivors while bringing them up-to-date information delivered by experts from their own communities.

"The Coalition's regional educational seminars help us connect with survivors in our community," says registered dietitian Christina Ganzon of Finger Lakes Health. "Survivor nutrition is often overlooked as the focus is primarily on nutrition during treatment and preventive. However, I think survivors are very motivated to change their nutrition to improve their health and lower the risk of breast cancer recurrence."

Carol Kistner, a survivor living near Batavia, had this to say about our regional evening educational seminars: "The practitioners brought to our community by the Coalition offer a wealth of knowledge on various topics related to this disease. But even more valuable to me than this added knowledge is the opportunity to engage with other survivors and their families. These women and men of grace renew my hope."



Amy Miller, registered dietitian speaking at the Batavia evening seminar in June



Christina Ganzon, registered dietitian speaking at the Geneva evening seminar in March

Thank you to our wonderful community co-sponsors who supported our recent regional evening educational seminars:

- Dansville Public Library
- Dormann Library
- Finger Lakes Health
- Geneva Public Library
- Interlakes Oncology and Hematology
- Orleans Community Health
- Rochester Regional Health | UMMC-Batavia
- Senator Patrick M. Gallivan (NYS 59th District)
- Senator Michael Nozzolio (NYS 54th District)
- Senator Thomas O'Mara (NYS 58th District)
- Senator Robert G. Ortt (NYS 62nd District)
- Senator Michael Ranzenhofer (NYS 61st District)
- UR Medicine | Noyes Health
- UR Medicine | Wilmot Cancer Institute

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Continued on back cover