

Breast Cancer Coalition

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

Community Roots, Grass

Roots! -By Tracy Brown

Gross roots. When we introduce the Breast Cancer Coalition to new people we meet, we tell them “We’re a grass roots organization.”

Google defines “grass roots” (noun) as “the most basic level of an activity or organization” and lists the synonyms “popular” and “of-the-people.”

In the Spring 2013 issue of *Voices of the Ribbon*, the Coalition’s Executive Director, Holly Anderson, included the following in her column: “Grass Roots: We are governed by a Board of Directors comprised of members of our own community. More than half of these Directors are personal stakeholders, having experienced their own diagnosis of breast cancer. Others have been touched by breast cancer through partners, friends, or family members. Together we set the course for our work. Because we are all members of this community, we have firsthand knowledge of the challenges faced and, thus, have a personal stake in the success of our solutions to these challenges.”

Holly’s words made me think of one of those grass roots synonyms: *of the people*. The Coalition is made up of many survivors who’ve been diagnosed with breast or gynecologic cancer. It’s made up of their family and friends as well. This community has “firsthand knowledge” of how a diagnosis changes a person’s life. And there is often a great personal stake involved in our work and its outcomes. Our community is the survivor community. From the “grass roots,” we rise up to make a difference.



Now Welcoming Women with Gynecologic Cancers

BCCR.org/regional

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Let’s Meet for Coffee!

Ladies in Dansville get together for Survivor Coffee Time at least once per month at a local cafe.

Our efforts have taken us into regions outside of Monroe County. We’ve met survivors in every corner, and it’s not surprising to find “grass roots” groups growing in these places, too. In the past, we’ve spotlighted the Finger Lakes Breast Cancer Support Group – an informal group of survivors that has been meeting in Geneva since 1991. Another “women’s cancer group” meets monthly in Dundee. More recently a “survivor group” formed in Dansville as a result of our Gentle Yoga program offered there. They meet every three weeks for coffee at a local cafe. The Coalition program brought them together – the coffee and camaraderie keep them going! (*All groups welcome newcomers. Contact Tracy at the Coalition for more information.*)

In our travels throughout the region, we’ve learned of survivors creating comfort bags for those in treatment, communities coming together for local fundraising events, and survivors gathering in support of one another. This is the result of good people joining forces to make a difference for those living in the aftermath of a cancer diagnosis.

We are grass roots. They are grass roots. Together, we’re making a meaningful, positive impact on our Central and Western New York communities. ☺

We’re always in search of community-based, “grass roots” groups! Do you know of a group or organization in your area that serves the survivor community? We want to know more! Contact the Coalition’s Tracy Brown at tracy@bccr.org or call 585-473-8177, ext. 310.

Survivor Spotlight -By Tracy Brown



Betty Sue Miller — spirited, full of life, a dynamo. She's also a wife to Fred, mother of Kevin and Janet, grandma to furry four-legged family members, and a Library Director in Albion. On a sunny summer morning, we met and talked about her breast cancer journey that began in March 2013.

It all started with a routine mammogram. Betty Sue Miller hadn't found a lump, hadn't gone in for her screening with any expectations other than she was healthy and fine. A retired teacher, Betty Sue still subbed at an alternative school in Orleans County. In fact, she was working at the school on the day she got the call.

"I was stunned," Betty Sue remembered. "So there I was, with kids who might not do as well in more traditional school settings. My cell phone rings, I excused myself, and the voice on the other end said, 'I'm sorry to tell you this, but you have breast cancer.'"

Betty Sue left the school and collected her dear friend, her daughter, and her son-in-law. They sat together at a restaurant and cried. "But even then," said Betty Sue, "I wasn't scared. I just knew that this was going to be a nuisance. I felt like this is a 'normal abnormality.' It [breast cancer] is everywhere."

The cancer was in her right breast. Betty Sue's next step was to consult her family doctor, who referred her to a surgeon. When that particular surgeon was unavailable, she opted for another one from the same practice. A lumpectomy was scheduled and, unfortunately, abruptly cancelled by the doctor at the last minute. Betty Sue needed to reschedule her procedure. "I think it would be important for people facing surgery to know what would happen if their surgery was cancelled unexpectedly," she emphasized. "What would be the plans then?"

To her frustration, her surgery was rescheduled for June. But, she admitted, "None of us is all good or all bad. He did a fabulous job with the surgery. He just wasn't right for me. I need somebody who is going to talk to me. I didn't want to be the only one talking." She didn't see the surgeon again after the surgery.

Betty Sue believes it's important for individuals facing a cancer diagnosis to feel good about the physicians they are engaging as part of their medical team. "I love my medical oncologist!" she added. She met with him for a consult prior to her surgery and their attitudes just clicked.

After surgery, Betty Sue's sentinel lymph node was found to be cancer free. Believing her next step would be radiation therapy, she consulted with a radiation oncologist. During this appointment, she learned that there was more to her diagnosis than originally thought. The recommendation was for her to have chemotherapy first and she was referred back to the medical oncologist.

"That was an even bigger surprise than the breast cancer," Betty Sue said. "I thought we were going to cut this out, do a little radiation, and life is good."

Chemotherapy started in July and was completed in mid-fall. Because Betty Sue's cancer was found to overexpress the HER2/neu protein - a growth factor in some breast cancers - she received the drug Herceptin in addition

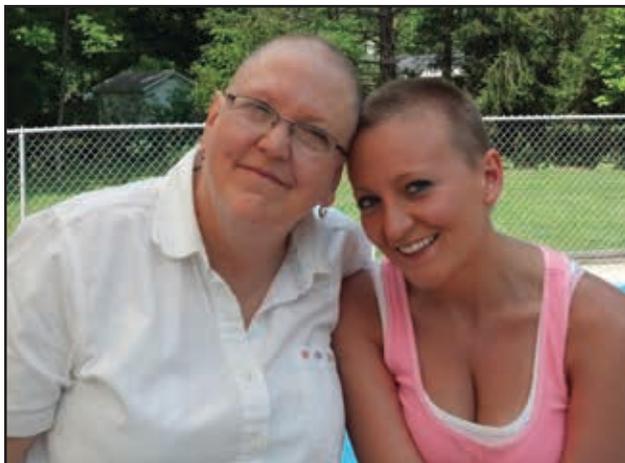
to her chemo regimen. Betty Sue found her treatment was both okay and challenging, depending on the day. Through experimentation, she learned coping skills that worked for her. For example, she couldn't stand to drink anything until she discovered she could drink water through a straw with a Werther's Original candy in her mouth. And despite an aversion to many foods, she ate both peanut butter and eggs daily, and they tasted great! Onion soup worked, too.

Radiation followed, and Betty Sue drove herself daily to treatment. She finished by the

end of January 2014. For her, radiation was a "walk in the park." She would go for her appointment and then out to lunch. Noting that her radiation oncologist and his staff were great, Betty Sue was, in fact, invited to join the staff football pool... *and won!* "When the staff brings you into their family, what a difference," she added.

Betty Sue reflected on her medical and her radiation oncologists. "You learn about the people taking care of you, how they entered their fields, and you find out that they are just as human as you. What a fabulous thing that is!"

In early 2015, Betty Sue accepted a position as interim director of the local library; this became a permanent appointment a few months later. Her second breast cancer was found in March 2016 - again, by a routine mammogram. This time the cancer was in her left breast. She was at the library working late, waiting for her husband



Betty Sue with her daughter, Janet

Fred to arrive with pizza, when the call came.

“And then a friend of mine, another breast cancer survivor, walked into the library. I asked, ‘What are you doing here?’ She had come to give me a hug. She knew I went for a mammogram, and she wanted to learn how it went. I brought her back to the office and told her that I had just found out that I had breast cancer again. She stayed with me until my husband arrived.” Betty Sue paused, “I was so grateful to Kathy, so grateful.”

Betty Sue returned to the surgical practice that she had gone to the first time, but chose a different surgeon. “I adore this man,” Betty Sue confessed.

They talked about genetic testing and Betty Sue elected to do it. She tested positive for the BRIP1 gene mutation and was told that she had an elevated risk for breast cancer and ovarian cancer. Her daughter also tested positive and has the same elevated risk. Betty Sue would eventually have both ovaries removed.

With her second breast cancer diagnosis, Betty Sue opted for a bilateral mastectomy without reconstruction. “I have had no regrets,” she said. This time she did not need additional treatment after surgery; however, she continues to take an aromatase inhibitor (a medication used for hormonally-fueled tumors).

Betty Sue brought up the importance of self-advocacy. The day after her surgery, the hospital wanted to discharge her but neither she nor her family was ready for her to return home. She needed additional instruction for recovery care – and more rest. Her nurse agreed. Betty Sue stayed a second night. “Do advocate for yourself,” she said.

Her family was incredibly supportive during her recovery, and she cuddled frequently with Stanley, her Bassett Hound. He was the best therapy.

As the conversation came to a close, we asked Betty Sue for her final thoughts. She noted an article in the paper, written by a minister. It was called *The Gift of Illness*. At first she thought, *yeah, right*. “But there are gifts – there are, if you allow yourself to see them.” She doesn’t sweat the small stuff anymore.

Betty Sue offered this advice to those facing a diagnosis of cancer: Talk. Talk to anyone. If someone isn’t listening to you, find another person who will. She noted that she enjoys attending the Coalition’s Breast & Gynecologic Cancer Support / Network Group held twice monthly at the Hoag Library in Albion. “It’s been wonderful!” she said.

She’s grateful that she was able to work during her second diagnosis. “It was something to look forward to. And this,” Betty Sue finished as she considered her breast cancer journey, “has been a bump in the road. It’s just a bump in the road. Right now, I’m whole.” ☺

*“Talk. Talk to anyone.
If someone isn’t listening to you,
find another person who will.”*



At the Biltmore in North Carolina

What’s Going On?

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

Join our mailing list and learn when we are holding an event or offering a program near you!

Contact Tracy Brown, Regional Programs and Outreach Director, at 585-473-8177 or email her at tracy@bccr.org and request to be put on the regional notification list.

Thank You!



Thank you to speaker **Hannah C. Smith, RDN, CDN**, a Registered Dietitian Nutritionist and the Eastern Region Clinical Nutrition Manager for Rochester Regional Health, for presenting on *Healthy Choices: Breast Cancer Survivors & Nutrition* at our October Newark, NY educational seminar.

A Q&A with Mindfulness & Meditation Teacher Rick Lynch

In this issue, we're featuring a Q&A with Certified Meditation and Mindfulness Teacher Rick Lynch. Rick leads this Coalition's program for survivors in Canandaigua. We asked him to share some thoughts about our program and its participants.

Who participates in Mindfulness & Meditation classes?

Any breast or gynecological cancer survivor – including those going through treatment – is welcome. They range in ages from 30-something and up! They are from all walks of life, most working, some retired. They are busy people who are looking for tools in their lives to help them deal with the stress cancer brings.

Can survivors enroll even if they haven't taken a Mindfulness & Meditation class before?

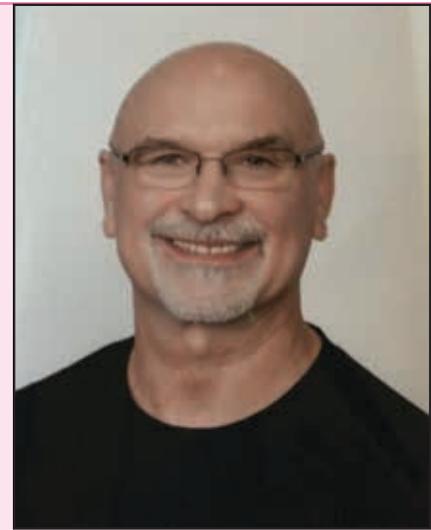
This practice is for anyone who wants to try it for the first time and also for people who have been doing it for years. It is a simple practice using our breath, sensations, and relaxation to deepen our awareness of the present moment. There is an energy that comes from the group when they are together.

What should program participants expect when they come to class?

When participants come to the Mindfulness & Meditation program, they will be in a safe, neutral environment with emphasis on comfort. Most sit in chairs, a few sit on the floor. There is time to talk and share their feelings and emotions. They learn relaxation techniques, breathing for stress, and tools for having a regular home practice.

How might breast and gynecologic cancer survivors benefit from the Mindfulness & Meditation program?

The practice will help with the rollercoaster of emotions cancer can cause. Being with others to share these experiences and to receive their support helps everyone. We take a breath around 21,000 times a day. Coming back



to our breath as a tool brings the mind back home to the body again and again. This will help to be more grounded in the present moment, not in the past or projecting to what could happen in the future. This is a practice of calm and abiding. Of body and mind benefits. Breathing... Mindfulness... Awareness... STILLNESS.

** The Coalition recommends that individuals consult their physician before participating in any wellness program.*

Learn more about Regional Programs! We offer them in several cities / towns outside of Monroe County. Contact the Coalition at 585-473-8177 or email Tracy Brown at tracy@bccr.org to learn what is available.



Fundraising in Honor of a Friend

Wow! Thank you! Members from Scottsville Volleyball present a \$1,500 check to the Coalition in honor of fellow player, Pam Polashenski, a regional survivor. Funds were raised at the Summer Redneck Throwdown in August. Left to right: Heidi Klossner, Reagan Burns, Holly Anderson (the Coalition's Executive Director), and Pam Polashenski.



Please join us Thursday, November 30th 5-7pm

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