

Survivor Spotlight: Michele Mayer



Michele Mayer was just 35 in 2005, when she was diagnosed with breast cancer. At about the same time, Michele's mother, Marjorie, received a similar diagnosis. Sadly, Marjorie passed away in 2009. However, through these early years, the two women provided each other with direct support, remaining open with one another about

their medical choices and what they learned along the way.

Michele was an active woman, busy with her church and volunteer activities while serving as Program Director for the Family Service Society, Inc. in Corning. It was during a routine appointment in 2005 that concerns arose.

A dimple in her breast had developed over the prior year. No lump could be felt, but by the time she went for her exam, her armpit felt "full," as if a vine was growing under the skin. About two weeks before her appointment, the skin had taken on the appearance of an orange peel. Following a mammogram and ultrasound, her gynecologist told her she had breast cancer.

Michele underwent chemotherapy, both before and after her bilateral mastectomy. Surgery was followed by 34 treatments of radiation at the Falck Cancer Center in Elmira. Michelle's surgical pathology revealed a breast cancer that was estrogen and progesterone receptor positive, which meant that those hormones fueled the growth of her cancer. Michelle, a premenopausal woman, was prescribed a five-year course of the drug Tamoxifen, the anti-estrogen medication of choice for someone in her position.

After seeing a medical professional at least every week (and more frequently during radiation), Michelle found it difficult to face that, all of a sudden, she would not have that continual supportive contact. A social worker from the Falck Cancer Center connected her with another survivor so she would have someone to talk to. Michelle also started attending the Women Surviving Cancer support group at the Center.

After five years of Tamoxifen, Michele was not completely menopausal, and, in an effort to minimize the amount of estrogen in Michelle's body, her doctor tried to induce menopause with injections of Lupron. This didn't have the desired effect, but caused tendonitis in one arm. This, in turn, exacerbated the lymphedema (swelling that can sometimes occur after surgery) Michelle had been experiencing.

In 2012, fluid was found in the pleural area around Michelle's lungs. Upon testing, this fluid was found to contain cancer cells. Biopsies of nodules in her pleural cavity were taken and revealed that breast cancer was present. At the same time, Michele had a procedure to close the pleural space. Since then, cancer in her pleural lining has shown up on PET Scans.

Because Michele's original breast cancer and recurrence were estrogen and progesterone receptor positive, she had a

complete hysterectomy in 2012 to eliminate that source of estrogen. In the years since, she has taken several different anti-estrogen medications and, at the time of this writing, is scheduled for another PET Scan to evaluate the effectiveness of her latest regimen.

After sharing her breast cancer story with the Coalition, Michele noted that many women will not or cannot advocate for themselves. We asked her to elaborate. "If there is something that my doctor recommends or I believe would be best for my health, I am going to do all I can to get that," she said. "Bottom line: I do not accept 'no' when it comes to my health and wellbeing."

Michele also suggested that if you are someone who doesn't easily advocate for yourself, find someone – a friend, a family member – who is willing to help you. She added how important it is to have doctors who are willing to advocate for their patients as well, to help them get the tests, treatments, and medications they need.

Through a friend, Michele learned about the Coalition's programs. Along with a couple of evening educational seminars, Michele has attended three Advanced Breast Cancer Seminars. "Each time I attended, I came away with some new information.

Since I believe knowledge is power, I have found them to be very beneficial," she told us. "It is always nice to be in a room with others going through some of the same challenges I have faced or may face in the future."

Michele also plans to become a PALS mentor through the Coalition. "I believe part of my journey with breast cancer is to help others on their journey. I have had the opportunity to do this in a group setting, and I would like the opportunity to do this one-to-one as a PALS mentor."

When asked what advice she would give to herself back in 2005, Michelle replied, "Be willing to let others help out more. My mom and I were quite independent, and because we had each other (and of course others knew that), we just naturally relied on each other. Maybe we built a proverbial wall around ourselves."

"It took my recurrence in 2012 and three medication changes to really come to terms with the fact that indeed my cancer journey is apt to be wrought with cancer cells no longer responding to medications and having to make changes. With that in mind, my one hope and prayer is that 'science' stays at least one step ahead of me."

For those who want to support a friend or family member through diagnosis and treatment Michele advises, "Do not say 'call me if you need anything.' Often we do not know what we need, and in my case, I know how busy everyone is. I am not apt to call. Instead, call the person if you have an hour or so to see if they have something you can help out with. Let them know you are going to the store. Ask if they need anything. Or, if you have made a meal and have extra, just drop it off."

"It is the little things that mean the most." ☺

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

During our October round table discussions, some breast cancer survivors told us that they've attended Coalition events and made connections with our staff. Others, learning about our free programs for the first time, asked us what is available for them now. To learn more about any of these programs, please call 585-473-8177 or email us info@bccr.org.

Breast Cancer 101 (BC101) is a chance for a newly-diagnosed person to stop the whirlwind of appointments and decision-making and take a breath, sit down, and talk one-to-one with one of our trained staff members, who can help review the available options and empower the individual to move forward in the best possible way. BC101 consultations usually take place at our facility, but our trained staff is available to talk on the phone if travel is difficult.

Peer Advocates Lending Support: PALSSM is a unique mentorship program in which a newly-diagnosed individual is connected to a breast cancer survivor who had a similar diagnosis and treatment plan, and whose life situation is also similar. PALS mentoring can be provided through one-on-one meetings, over

the phone, and through email. A "PALS Pak" of comfort items tailored to each survivor's needs is also available.

Our **Annual Cindy L. Dertinger Advanced Breast Cancer Seminar: Tools for the Journey** is held in early spring at the Memorial Art Gallery in Rochester. Seminar speakers include members from the region's medical community, as well as one or two survivors living with metastatic breast cancer. A short reception follows the program. **This year's 13th annual seminar will be held on Friday, April 8, 2016.** Breast cancer survivors of all diagnoses, family members, supporters, and health care providers are welcome to attend. RSVP's are requested. Please contact the Coalition for more information or to be added to our invitation list.

We hope you will be able to take advantage of one or more of our programs. Please see pages 9-10 of this issue, contact the Coalition at 585-473-8177, or visit our website at www.bccr.org/programs/ to learn more.

We hope to hear from you – and see you – soon.

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

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 & Yates Counties
Call: 315-462-0602

Steuben County
Call: 877-778-6857 or
607-324-8812

Wayne County
Call: 315-332-2255 or
1-800-854-8439

Spotlight on....

The Finger Lakes Breast Cancer Support Group

One of the most rewarding experiences of our regional outreach project is learning about local, grassroots breast cancer support groups that grew out of a need. While exploring resources in and around Geneva, NY, we were directed to contact Gail from The Finger Lakes Breast Cancer Support Group.

The Finger Lakes Breast Cancer Support Group began meeting in 1991. An informal group, local women who face a diagnosis of breast cancer meet monthly (sometimes every other month during winter) to share information and provide support for one another.

Gail, a long-time breast cancer survivor, told us that group members are willing to meet with those who are newly diagnosed, either before surgery or any time after. Group members provide non-medical guidance, and are willing to talk about their own experiences with surgery, chemotherapy, radiation, and reconstruction.

If you live or work in or around Geneva and are looking for support, you can reach out to Gail at 1-315-585-6625 for meeting dates and location. Please leave a message if you reach voice mail and she will return your call. ☺

Breast Cancer Coalition of Rochester **BCCR**

VOICES OF THE Fingerlakes Region of Central & Western New York

BCCR.org/regional

Volume 1
Number 1
Winter 2016

Fall 2015 Breast Cancer Survivor Round Table Round-Up -By Tracy Brown

In October 2015, the Breast Cancer Coalition facilitated six round table discussions throughout the Finger Lakes Region of Central and Western New York to hear directly from breast cancer survivors living in those communities. We were grateful to have the support of six New York State senators and their exceptional staffs who not only hosted these discussions on our behalf, they sent messages to their constituents to help us “get the word out” about the events.

Round tables were held in Bath, Dansville, Geneva, Warsaw, Medina, and Batavia. Breast cancer survivors from diverse backgrounds, diagnoses, and experiences came together in a safe space to discuss what happened after hearing the words, “you have breast cancer.”

We asked what resources they were given when they were diagnosed. To where did they turn for support or help? What resources did they find in their communities? What resources were they able to access? What did they *wish* they had access to at any point following diagnosis?

Survivors shared their stories. We listened. We asked questions. We asked more questions. We learned about the challenges faced by breast cancer survivors throughout our region. Their stories ranged from difficulties in traveling to treatment; to maintaining “good” insurance coverage; from finding the “right” information about breast cancer - while



Senator Nozzolio and Holly Anderson



Senator O'Mara and Holly Anderson led the discussion



Holly Anderson with Senator Young

Round Table Wrap-Up continued

avoiding rumors or half-truths - to rebuilding strength in their bodies; and so much more.

And at every round table, a common theme arose: breast cancer survivors in these regional communities crave support. While support from families, friends, co-workers, and churches is important and abundant, the unique support provided by other breast cancer survivors is often missing.

We watched as personal connections were made around these tables: survivors “finding” each other; survivors nodding in agreement when mutual concerns and fears were voiced – sometimes, for the very first time; survivors sharing resources they found on their own, such as a local yoga class or another wellness program. They took notes. They asked questions.



Holly Anderson with Senator Ranzenhofer

by breast cancer survivors, what opportunities exist, and what steps to take next. We want to collaborate with those currently providing resources for survivors and look for ways to extend and enhance this support.

Our most heartfelt thanks are offered to Senator Michael F. Nozzolio, 54th Senate District; Senator Catharine Young, 57th Senate District; Senator Thomas F. O'Mara, 58th Senate District; Senator Patrick M. Gallivan, 59th Senate District; Senator Michael H. Ranzenhofer, 61st Senate District; and Senator Robert G. Ortt, 62nd Senate District. Your continued steadfast support of the Coalition's work will make a difference in the lives of breast cancer survivors in your communities. ☺



Senator Ortt welcomed round table attendees.

And they gathered together after the events. Contact information was exchanged and new relationships began.

This is why we are extending our reach into these communities. We need to learn what resources are already there, what is desired

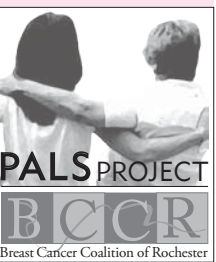


Tracy Brown, the Coalition's Regional Outreach Director, shares a smile with Cynthia Printup-Harms, Director for OAHIO, Native American Independent Living Services (Buffalo) at the Tuscarora Nation Health Center's "Healthy Harvest Fair" in Lewiston.



Save the Date:

Saturday, February 6, 2016



The next P.A.L.S. (Peer Advocates Lending Support) training has been scheduled for breast 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, P.A.L.S. Coordinator at 585-473-8177 or pat@bccr.org for more details and to receive a P.A.L.S. training application.

Continued on next page

Breast Cancer Coalition of Rochester
1048 University Avenue Rochester, NY 14607
Office: 585-473-8177 • Fax: 585-473-7689 • Online at www.bccr.org