

**Regional Survivors Attend Peer Mentor Training in Rochester**

-By Tracy Brown

**BCCR.org/regional**

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On a beautiful, sunny day in February, the Coalition held its PALS<sub>SM</sub> (Peer Advocates Lending Support) Mentor training, bringing together survivors from around the region.

Specifically developed to meet the particular needs of those diagnosed with breast cancer, PALS is a unique peer mentorship program in which someone newly diagnosed with the disease, or at any point during treatment or recovery, is connected with someone who faced a similar situation in the past and is doing well. PALS mentors can provide helpful insight and compassionate support that the mentee needs.

Breast cancer survivors traveled to Rochester from Genesee, Livingston, Ontario, and Wayne Counties, joining others from Monroe County in a day of learning, role playing, and resource sharing. Led by Coalition staff and a licensed therapist, this training session featured discussions on effective listening, building healthy boundaries, and understanding the role of the mentor in empowering the mentee.

After a tasty lunch provided by the Coalition, attendees jumped



*Regional PALS mentor trainees Debbie Weis and Maryann Haigh*

right back into training and were treated to some fun role playing activities led by staff. After a few “performances,” trainees paired off to practice some of the skills they learned earlier in the day.

It’s important to build a broad network of trained PALS mentors that the Coalition can turn to when we get a call from outside Monroe County. While mentors can, and sometimes do connect with their mentees by phone and email across the miles, ideally we would be able

to assign those who contact our office a PALS mentor living close by.

Regional survivors attending the February PALS training understand this need. They represent the first wave of survivors called to become mentors as a result of our outreach into the region these past fall and winter seasons. They know all too well the challenges that survivors living in more rural areas face. They also know how to be resourceful, and want to empower others who are

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*Round Table Wrap-Up continued*



*Nancy Johnsen and Carol Kistner participate in a role playing exercise*

dealing with a diagnosis of breast cancer.

This is the ninth year that the Coalition has offered PALS Mentor training. As we move toward our 10th year, the Coalition will continue to grow a network of compassionate mentors so that no one in the Finger Lakes Region of Central and Western New York has to go through breast cancer alone. ☺

**REGIONAL BREAST CANCER SURVIVORS:**

*We need YOU! Learn more about becoming a peer mentor. To request your volunteer PALS application and for answers to your questions, please email PALS Coordinator Pat Battaglia at pat@bccr.org. Or, call the Coalition at 585-473-8177.*



*Peg Jacobs and Liz Mercado*



*PALS mentor training attendees having a lively discussion*

*Survivor Spotlight continued*

before serving 20 years in the Army inactive reserves. He retired in 1998 as a Master Sergeant E8. Now a volunteer, Owen drives a medical transport van and has raised over \$60,000 for vans for the VA in Albion. He considers himself fortunate. Physically and mentally he can do a lot of things that some veterans cannot.

Owen still takes a hormonal medication daily, and weekly he takes an experimental medication designed to restore sensitivity to the hormonal drug. Once per month he gets a little “pellet” injected in his stomach. He trusts his doctors, noting that his oncologist gives him options, but always says the decisions are Owen’s to make. He deals with the side effects of his treatment, physical and mental. He’s learned to say thank you “for one more day.”

“Let’s just step back and look at this situation,” Owen says with a twinkle in his eye. “I tell people, I get up in the morning and I look at the bottom of my feet. There’s no expiration date. So I go along with the day.”

Owen encourages people to listen to their bodies. If there’s a problem, he says you need to find out what that is. Talk to the experts, listen to the people who know what they are talking about, and do what they tell you to do. And get on with the business of living.

“I have cancer. Some people have lost an arm in a war. Some people are bipolar. Some are losing their hair. It’s just another part of life.” ☺

**Steuben County Cancer Services Program**

In our last issue, we neglected to include contact information for Steuben County in a list of regional cancer screening programs. We regret the oversight and have provided the information below.

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

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

## Survivor Spotlight -By Tracy Brown



**Owen Toale** – husband, father, grandfather, veteran, volunteer, youth baseball coach, former newspaper editor and disc jockey, retired property and transportation general manager, and small business owner – was first diagnosed with breast cancer in 2002.

We first met breast cancer survivor Owen Toale at a round table discussion hosted by Senator Robert Ort in Medina, NY. Inspired by his story, we asked to share it with our readers. Owen obliged.

One day, as Owen was changing his shirt, his wife noted an inverted nipple. At first he brushed it off as a cyst, something that could be easily taken care of later. But his wife encouraged him to get it checked quickly.

He made an appointment with his primary care physician, and ended up seeing a different doctor from the practice, who sent Owen for a sonogram. Immediately afterward, a mammogram was ordered. The doctor reading the mammography results delivered the news directly: “I believe you have breast cancer.”

Owen was taken aback. Coincidentally, his primary care physician was in the building and called into the office; the recommendation was to see a surgeon. Following a biopsy, Owen had a mastectomy. The pathology report confirmed breast cancer, the stage of which was listed as between 2 and 3.

It was recommended that he find an oncologist. After some consideration, Owen chose to go to Roswell Park Cancer Institute. During the first consultation, his new oncologist wrote on a whiteboard: Tamoxifen: 85% non-recurrence. Mild chemotherapy and aggressive chemotherapy: 80% and 85% non-recurrence.

Foregoing chemotherapy, Owen opted to take Tamoxifen, and things went well for some time. However, 15 months later in 2003, blood work and CAT scans revealed that the breast cancer had returned.

At this point, Owen was given 37 radiation treatments. Unfortunately, he experienced skin burns as a side effect. A kind woman working in Radiation at Roswell told him about a gentle skin balm he could use, and he found some relief. It made things bearable.

After radiation was finished, Owen began another hormonal treatment. This one lasted seven years, with routine scans and blood work every three months before switching to a six months schedule. “I never got to the year thing,” Owen told us.

During a routine appointment at Roswell in October 2011, Owen waited in the exam room. The door was open and he watched his oncologist approach the room. “I have seen this man many, many times,” Owen said, “and I thought: he doesn’t look the same today.”

The doctor told Owen that his breast cancer had metastasized to his lungs. He had two tumors in one lung, and one tumor in the other.

Another hormonal treatment was begun. Then, in October 2015, a CAT scan revealed some slight tumor growth. Again, Owen’s doctors sought a different course of treatment.

“I have the utmost respect for [my medical team],” Owen said. “They’re are not just knowledgeable, they have such caring and concern for my well-being.”



Owen and his wife, Jan, celebrating their 43rd wedding anniversary.

The new treatment would involve injections: first every week, then every month, then Owen was moved to progressively longer periods between shots. When asked if he would like to be included in a clinical trial – a National Cancer Institute study with 600 participants – Owen agreed and enrolled as the only patient from Roswell. From what he understands, this phase is the

third stage of testing an experimental breast cancer drug, but Owen notes he could be taking a placebo.

When asked about genetic testing, Owen was thoughtful. “When I was first offered genetic testing, I didn’t know that breast cancer had been in our family. My maternal grandmother had breast cancer, but she passed away in 1938,” he said.

After learning about his grandmother’s diagnosis, Owen carefully considered his decision. “I don’t know how I could handle that information if I got [the results] and it wasn’t what I wanted to hear. I don’t know how I could go to my kids and say, ‘Listen guys...’” Here Owen paused. “You know, if I had daughters, I would have done it. But with two sons\*... I don’t know. So I decided no. This is my choice, and I’ve decided I’m not going to do it.”

We switched topics and talked about volunteering with the Veterans Administration. Owen was in the Air Force – four years active, followed by three years inactive reserves,

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\*EDITOR’S NOTE:  
Sons, like daughters, can carry these genetic mutations.

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

In our Winter 2016 Voices of the Finger Lakes Region of Central & Western New York, we shared three important Coalition programs/events that are open to survivors throughout the region: Breast Cancer 101; Peer Advocates Lending Support: PALS<sub>SM</sub>; and our Annual Cindy L. Dertinger Advanced Breast Cancer Half-Day Seminar.

In this issue, we would like to share more free educational opportunities, networking events, and supportive programs that we encourage you to join. Learn more about these opportunities: call 585-473-8177 or email [info@bccr.org](mailto:info@bccr.org).

**Evening Educational Seminars** are held January through October at 7pm on the fourth Wednesday of the month at the Coalition in Rochester. Topics range from understanding your pathology report, to nutrition after breast cancer, to the latest in surgery and reconstruction. Other past educational seminars have featured the role of the oncology social worker and highlighted the benefits of complementary therapies. No RSVP is required. Contact us to learn about upcoming topics!

**Young Survivor Soirees** are a GREAT way for younger breast cancer survivors to unwind, be pampered, and network with other young survivors! Held four times per

year on a Friday evening, past Soirees have included massages, craft beer and cheese tastings, balsamic vinegar craft creations, and more! **The next Soiree will be held on Friday, June 3.** Email [info@bccr.org](mailto:info@bccr.org) and request to be added to our invitation list – *RVSPs are required!*

### Networking Groups:

**Brown Bag Friday**, held every Friday at noon, is a great way to “dip your toe into the water” of our offerings. This informal networking group is hosted at the Coalition by staff. We encourage you to drop in – no reservations required! Gather a group of survivors from your community and carpool into Rochester to join us. Bring your lunch – we’ll provide dessert and beverages!

**Common Ground**, a networking group for those living with metastatic breast or gynecological cancer, is held at noon on the first and third Thursday of the month at the Coalition. This group is led by a family therapist, and lunch is provided. Please contact our staff to learn more and to RSVP so we can plan our lunch menu.

*Join us! We’d love to see you at one of our networking groups or at a special event. If you have any questions, we are here to answer them! Please contact the Coalition at 585-473-8177 or visit our website at [www.bccr.org/programs/](http://www.bccr.org/programs/) to learn about all our free programs for survivors. Any of our Rochester programs are open to regional participants. ☺*

## Regional Programs -By Tracy Brown

**Fulfilling YOUR Needs** – This spring the Coalition has been busy arranging regional evening educational seminars and piloting our first regional Healing Arts program – Gentle Yoga!

### Healing Arts Pilot

On March 3, we began a free 6-week session of Gentle Yoga classes for breast and gynecologic cancer survivors in and around Dansville. Led by yoga instructor Kate Drake, RYT/OTR, these classes focus on reducing stress, fatigue, and pain - while fostering creative movement in a safe environment.

Learn more about the Coalition’s regional activities.

Call 585-473-8177  
or visit our website at  
[www.bccr.org/category/regional/](http://www.bccr.org/category/regional/)

### March 10: Healthy Choices - Breast Cancer Survivors & Nutrition (Geneva, NY)

Christina Ganzon, a registered dietitian with Finger Lakes Health, spoke on types of foods and nutrients that are optimal for reducing recurrence risk and for maintaining a healthy weight after a breast cancer diagnosis.

### Community Co-sponsors:

The Geneva Public Library  
Finger Lakes Health  
Senator Michael F. Nozzolio  
(54th State Senate District)

### March 30: The Role of Chemotherapy in Breast Cancer - Before & After Surgery (Batavia, NY)

Dr. Nayana Ramdas Kamath, a medical oncologist at Wilmot Cancer Institute - Batavia, discussed how the presence or absence of three receptors, Estrogen (ER), Progesterone (PR) and Her-2/Neu can direct treatment protocols.

### Community Co-sponsors:

Senator Michael H. Ranzenhofer  
(61st State Senate District)  
Wilmot Cancer Institute - Batavia