Regional Survivors Attend Peer Mentor Training in Rochester

By Tracy Brown

On a beautiful, sunny day in February, the Coalition held its PALS, (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 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 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.

Nancy Johnson and Carol Kistner participate in a role playing exercise

Regional PALS mentor trainees Debbie Wasi and Maryann Haigh

PALS mentor training attendees having a lively discussion

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

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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

BCCR.org/regional
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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 mammogram 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%

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, 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.”

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…”

Owen notes he could be taking a placebo. “I don’t know how I could go to my kids and say, ‘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, before switching to a six months schedule. “I never got to the year,” Owen told us.

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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, and our Annual Cindy L. Deritinger 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@bcr.org.

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.

March 10: Healthy Choices - Breast Cancer Survivors & Nutrition

The Geneva Public Library

Finger Lakes Health

Senator Michael F. Nozzolio

(53rd State Senate District)

Common Ground, a networking group for those living with metastatic breast or gynecologic 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.bcr.org/programs/ to learn about all our free programs for survivors.

Any of our Rochester programs are open to regional participants. -

Learn more about the Coalition’s regional activities.

Call 585-473-8177 or visit our website at www.bcr.org/category/regional/

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

Learn more about the Coalition’s regional activities.

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