

# Breast Cancer Coalition

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

## *Terrific Twenty-three Travel to Albany!*

-By Tracy Brown

Now Welcoming Women  
with Gynecologic Cancers

[BCCR.org/regional](http://BCCR.org/regional)

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### **W**hat a fantastic way to leap into spring!

Twenty-three advocates traveled to Albany in support of the Breast Cancer Coalition and its regional work. Our fearless group consisted of survivors, supporters, staff, Board members, committee members, and regional program participants.

Our bus was rolling before 6:00am. Our mission: To meet with and thank the “Delegation of Eight” NYS Senators who vigorously fight for continued funding for the Coalition’s regional programs and outreach. We asked them to keep an eye on the funding request for a fourth year as the State budget is developed. We also met with the Senate Health Committee Chair, Senator Kemp Hannon.

Our voices heard, we posed for photos, made our good-byes, and celebrated a successful day in the Capital on a fun bus ride home! ☺

*Top photo: Representatives of the Breast Cancer Coalition met with Sen. Pamela Helming (NYS District 54) on March 19 to thank her for championing our important work in the region.*

*Bottom photo: Coalition staff and regional survivors met with Sen. Kemp Hannon (NYS District 6 and Chair of the Senate Health Committee) during our exciting trip to Albany.*

## Survivor Spotlight -By Tracy Brown



**Deb Nupp** – is a nurse, a daughter, a wife, mother to two, dedicated grandmother to three...and a survivor of both endometrial and breast cancer.

Deb Nupp is a born caregiver. It's hard to imagine a point in her life when she wasn't rolling up her sleeves and helping others. In fact, in 2006 she was busy caring for her father, who was living with colon cancer, while she worked as a nurse at a local hospital. Still, she managed to squeeze in a routine visit to her gynecologist in late February 2007.

During the exam, the doctor noted a possible cyst. She ordered an ultrasound and afterward, called Deb back for a biopsy. Aware of Deb's father's cancer, this doctor was particularly concerned.

It was St. Patrick's Day when her gynecologist called and left a message asking Deb, her husband Karl, and her daughter to come into the office on Monday morning to discuss the biopsy results. If Deb had any questions before then, she could call. Deb went downstairs to her father's cellar and phoned her physician, who described an aggressive cancer.

"I sat alone on the stairs and cried," Deb shared. "But the nurse in me needed to get it together. You have got to pull yourself together before you tell someone this news." She told Karl and her daughter, but chose not to tell her father at that point; he was having a difficult time with his own cancer.

Following the consult with her gynecologist, Deb was referred to a surgeon and an MRI was performed. She was booked for surgery within two weeks. Deb noted that it was "a robotic laparoscopic radical hysterectomy with pelvic lymphadenectomy." At the time, her surgeon was one of the few doing this type of surgery in Rochester; both Deb and her doctor were interviewed by a reporter.

"I think it was hard on the hospital staff sometimes because they knew me as a fellow employee," Deb reflected. Also a Caring Clown, she had developed humor programs for patients at the hospital. Prior to her surgery, she planned what she would have in her hospital room for comfort: a Winnie-the-Pooh pillow cover and a treasure chest filled with snacks, games, and prizes. The treasure chest brightened everyone's day. "I had plenty of visits from staff!"

Her tissue samples were processed by the hospital

where she had her surgery and three other cancer research hospitals outside of Rochester. Deb would be diagnosed with endometrial adenocarcinoma, stage 1-a, grade 3. While she would not require chemotherapy, she would need High Dose Rate Brachytherapy treatment to the vaginal cuff. Her first internal radiation appointment was on her birthday. This was followed by two more sessions over the next two and a half weeks. She was not allowed to be near her father or grandkids during this time – she could not expose them to the radiation. When Deb completed her radiation therapy, she was prescribed a vaginal dilator to help prevent atrophy of the vaginal wall. This was to be used daily for at least 10 minutes for the next several months. She admits this was emotionally difficult to use at times and believes other women could feel that way, too.

Deb began a routine of follow-up appointments every three months over the next two years, alternating between her surgeon and radiation oncologist. These included CA 125 bloodwork, pap smears, and an occasional CAT scan. Since 2009, she has alternated visits between her gynecologist and radiation oncologist every six months.

Sadly, her father passed away in 2008. Deb and her husband moved into her father's farm and she changed jobs. It was time to "get back to life." However, in April 2015 Deb would face a new diagnosis.

Deb paused as she remembered that day. It had been a routine

mammogram. Alone in a room waiting for the physician to come and talk to her about a suspicious finding, Deb was overwhelmed with thoughts of her family. "They shouldn't stick you in a room by yourself to wait," she said. An ultrasound and a biopsy were performed, and the diagnosis was breast cancer.

Within days she had an MRI. It showed the spot in her left breast revealed by the mammogram, plus two additional spots on the lower left side of the breast. After another biopsy, it was clear Deb would need a mastectomy. Because of her health history, she opted for a bilateral mastectomy.

Deb's granddaughter was just getting ready to graduate from college with high honors, while both grandsons were in the middle of final exams. Deb chose to keep her diagnosis to herself, Karl, and her two children. After meeting with



*Deb's beautiful grandchildren*

***"Bring your questions to appointments. Bring someone with you to write down answers. The empowerment is within you."***

her breast surgeon – a physician she knew well from work – she asked if she could schedule her surgery further out so she could be present for her granddaughter’s special day. Her surgeon agreed.

The surgery was scheduled for June 10, 2015. Deb waited until the day before to share her diagnosis and surgery plans with her grandchildren. She also sat down with her husband and showed him online photos of post-mastectomy images so he would have some idea of what to expect.

The surgical pathology revealed that Deb’s breast cancer was invasive ductal carcinoma, stage 1A, grade 2. Her cancer was hormone receptor positive (i.e., estrogen and progesterone drove the cancer’s growth), but tested negative for HER2/neu, a growth factor in some cancers. No lymph nodes were involved. Further treatment was decided by a tumor board review using Deb’s cancer history, pathology results, and Oncotype test score of 14 (9% chance of cancer returning). She would not need radiation or chemotherapy. However, she was prescribed the hormonal therapy drug Tamoxifen.

Despite completing her arm exercises as directed, Deb noted continuing restriction of certain movements. She consulted her surgeon, who diagnosed her with cording (also known as axillary web syndrome) in both arms. Exercise is important to Deb, and she advises those recovering from breast surgery to communicate with their surgeons – especially if there is a problem completing the arm exercises that are prescribed. Let them know everything!

Deb considered different types of breast reconstruction before settling on implants. Again, she knew the physician who would perform the surgery. In October 2015, tissue expanders that had been put in place during her mastectomy were removed and permanent implants inserted. Deb would eventually need some revisions of the implant areas, including fat grafting, and those procedures were performed in January and December of 2016. Nipple tattooing followed in February 2017, with a touch-up in November of that same year.

Throughout her breast cancer journey, Deb did “a ton of research online,” but stayed away from blog sites until she knew what was accurate. She understood that different states have different regulations, and what one surgeon might report online could be different from what the protocol would be in her treatment and recovery plan.

Deb described her employer as “so unbelievable” in the level of support she received. At a staff meeting, Deb shared her diagnosis and gave each co-worker a white rose. Through it all, her co-workers were extremely helpful. “They set-up a meal train,” Deb’s eyes filled with tears. “We had a hot meal every night from the day I came home from surgery in June, until late August. Karl never had to cook, allowing him to care for me and tend to the farm.”

During our conversation, Deb admitted how angry she felt about her breast cancer. She had survived endometrial cancer, and now she had another cancer diagnosis to face. Before her bilateral mastectomy, she took pictures of herself naked from the waist up holding a sign that said, “this stinks” underneath her breasts. Little did she know that the photos would be helpful in determining the color of her tattooed nipples two years later.

Deb has a lot more she wants to do in life and has decided that the “primary person” in her life is herself. And the anger has gone away. “I wanted to live. I set small goals for myself,” Deb said. She even joined a weight loss support group and lost 75 pounds!

After participating in the Coalition’s Gentle Yoga program in Geneseo, Deb decided to become a peer mentor to offer support to others who have received a diagnosis of breast or endometrial cancer. In February 2018, Deb attended the Peer Advocates Lending Support (PALS) peer mentor training at the Coalition in Rochester. In March, Deb and Karl joined us in Albany to advocate for continued funding of regional programs for survivors.

Deb’s advice to those who are just beginning a breast or gynecologic cancer journey is this: “Ask questions! Bring your questions to appointments. Bring someone with you to write down answers. The empowerment is within you.” ☺

## *Thank you to our Terrific Twenty-three!*

Holly Anderson

Tracy Brown

Cecilia Burke

Rachel Burke

Patti Cataldi

Phyllis Connelly

Kathy Cunningham

Cindy Dykes

Ayanna Jackson

Peg Jacobs

Carol Kistner

Charlotte McCabe

Lori Meath

Beth Miller

Cynthia Nelson

Deb Nupp

Karl Nupp

Leni Rayburn

Lisa Smith

Miriam Steinberg

Lynn Sulyma

Ilonka Tumelaire

Dennise Webster



*Representatives of the Coalition sat down with Sen. Patrick Gullivan (NYS District 59) to discuss programs offered in his district. (Deb and Karl Nupp joined our group of Coalition Advocates!)*

## *Thank you to these NYS Senators for their invaluable support!*

**Sen. Pamela Helming, District 54**

**Sen. Rich Funke, District 55**

**Sen. Joseph Robach, District 56**

**Sen. Catharine Young, District 57**

**Sen. Thomas O'Mara, District 58**

**Sen. Patrick Gallivan, District 59**

**Sen. Michael Ranzenhofer, District 61**

**Sen. Robert Ortt, District 62**

**Sen. Kemp Hannon, Senate Health  
Committee Chair**



*All twenty-three Coalition Advocates joined Sen. Catharine Young (NYS District 57) for a beautiful photo in the Senate Chamber.*



*Coalition representatives were welcomed by Sen. Michael Ranzenhofer (NYS District 61) during our March trip to Albany.*

*Sen. Joseph Robach (NYS District 56) remains a strong supporter of the Coalition and our work in the Greater Rochester Area and the region.*



*Sen. Rich Funke (NYS District 55) posed for a photo after listening to survivors talk about the impact of regional programs. A portion of Sen. Funke's district stretches out into the region and survivors from his district have benefited from the Coalition's offerings.*



*Sen. Thomas O'Mara (NYS District 58) stepped off the Senate Floor to greet our Terrific Twenty-three!*