

THE JOHNS HOPKINS KIMMEL CANCER CENTER

# BREAST MATTERS

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THROUGH HEALTHIER WEIGHT  
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2020/2021

# BREAST CANCER CARE DURING THE PANDEMIC



throughout the pandemic, we now are able to see more than two-thirds of our patients in person.

Even during these challenging times, our drive to better understand and treat breast cancer and to continue our research on its prevention has not waived. We continued to provide care for patients receiving active therapy and those already enrolled in clinical trials. For the safety of our patients, new enrollment in therapeutic clinical trials was paused for a limited time period at the start and peak of COVID-19. When possible, trials were modified to decrease the total number of visits to the hospital, and care was delivered remotely and safely.

Now, with decreases in the number of cases of COVID-19 in our area and an increased supply of personal protection equipment, our experts are resuming some paused studies and making plans to ramp up more studies, as permitted by safety guidelines.

Our dedicated navigators transformed our programming, and our support group attendance has been higher than ever. We conducted a three-part webinar series related to COVID-19's effects on breast cancer care.

As always, the health and safety of our patients are our top priority. We are excited to bring you these stories of exciting progress in survivorship, prevention, treatment and research.

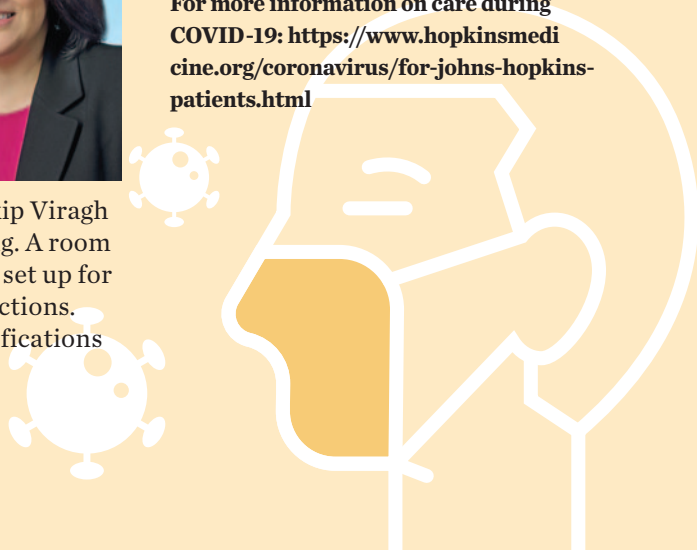
**Vered Stearns, M.D.**  
*Breast Cancer Program Director*

**For more information on care during COVID-19:** <https://www.hopkinsmedicine.org/coronavirus/for-johns-hopkins-patients.html>

**OUR PRIORITIES ARE** unwavering, even during this unprecedented time of the COVID-19 pandemic. Our experts continue to provide excellent care and advance breast cancer research. We implemented innovative measures to ensure the safety of our patients, their families and our care teams. Our entire breast cancer team worked together with experts in medical, surgical and radiation oncology, and pathology, creating modified guidelines for breast cancer treatment to maximize the benefit of therapy and decrease the risk of therapy-related complications and contracting COVID-19. Our published recommendations were shared with other cancer

care providers across the nation and the world and adapted as industry standards.

Our innovative nurses initiated a drive-through injection clinic, allowing patients to safely receive injectable treatments in the circle in front of our Skip Viragh Outpatient Cancer Building. A room in the building's lobby was set up for blood draws and some injections. With these and other modifications



# HOW HEALTHY SLEEP AND WEIGHT MAY IMPROVE SURVIVAL

## New Study Focuses on Improving Sleep to Aid Weight Loss

**TRIPLE NEGATIVE** breast cancer survivor Jennifer was overweight and depressed when she learned about the Cancer Obesity/Overweight Insomnia Study, known as COIN.

“I was sleeping all day. I didn’t want to do anything. I felt like my life was going nowhere,” says Jennifer. “The COIN study literally changed my life.”

Medical oncologist, breast cancer expert and **Fetting Fund** researcher **Jennifer Sheng, M.D.**, says weight gain after diagnosis is a serious matter and quite common. Over one-half of breast cancer patients struggle with excess weight, and this adversely impacts quality of life. Women who are already overweight when diagnosed may be

most affected. Excess weight may even increase the risk of the cancer coming back by 40% to 50% and the risk of dying from their cancer by 50% to 60%.



Insomnia further complicates matters. **Janelle Coughlin, Ph.D.**, COIN study leader and Associate Professor of Psychiatry and Behavioral Sciences, says 20% to 70% of cancer patients are sleep deprived, and this alone has been linked to poor outcomes. Further, she says, research finds that sleep deficiency undermines weight loss efforts.

“Targeting sleep may be a critical and neglected component of weight loss treatment,” says Coughlin.



With a pilot grant from **Under Armour**, which is dedicated to women’s health and fitness, Coughlin, Sheng, sleep expert **Michael Smith, Ph.D.**, Director of Behavioral Medicine and Psychiatry at Johns Hopkins Bayview Medical Center, and Breast Cancer Program Director **Vered Stearns, M.D.**, embarked on a study to promote both healthy sleep and healthy weight in cancer survivors. Working together, they built upon the success of an earlier clinical study called POWER (see <http://bit.ly/2ZPOWER> for more information), a telephone and web-based remote weight loss coaching program, adding a sleep component.

Noting that patients often struggle to achieve weight loss on their own, the POWER and COIN studies used behavioral approaches to help patients with weight management. “Helping breast cancer survivors tackle weight management is a mission within our entire department,” says Sheng.

In COIN, there was an added a focus on sleep disturbances and insomnia, and how they may impact weight and metabolism.

“We are interested in seeing if we treat sleep conditions, can we get better outcomes with obesity treatments,” says Coughlin.

Jennifer began the study six months after her mastectomy. Her surgeon told her she got all of the cancer, which was great news, but Jennifer says she still didn’t feel healthy.

She was overweight before her cancer diagnosis, but after the surgery, she gained more weight. Then she received an email about the COIN study, and things began to change for her.

The first part of the COIN study addresses insomnia. Sleep deprivation, Sheng says, results in changes in the hormones that suppress appetite and cause the body to expend less energy. Lack of sleep can cause people to consume more calories at night, Coughlin notes, adding that sleep-deprived people are also more likely to engage in impulsive eating and make higher-calorie food choices.

Jennifer had fallen into a pattern of napping frequently throughout the day and then had trouble sleeping at night.

After they ruled out a medical cause of her sleeping issues, such as sleep apnea, Jennifer began working with a sleep coach and kept a sleep journal to help her log and track her sleep patterns. Her coach recommended behavioral changes, including specific sleep and wake times; discouraged napping; eliminated television, electronic devices and reading books in the bedroom; and cut or limited caffeine. Each week, there was a new lesson and cognitive therapy to educate Jennifer about the importance of sleep and



Jennifer

worst fear was confirmed — she had triple negative breast cancer. Her daughters rallied around her, and her parents traveled from Florida to be near and help her through her treatment.

When her cancer treatment was complete, Jennifer began to focus on survivorship.

Janice was diagnosed at age 47 with lobular breast cancer. This type of breast cancer, although common, is challenging because it often does not present with a distinctive lump, which helps aid in earlier detection and treatment.

Her four-year treatment and recovery was marked by

complications that started when her pathology results revealed the cancer was more advanced than initially suspected, requiring she receive chemotherapy and radiation treatment in addition to surgery. She developed a serious post-mastectomy infection and had reactions to anesthesia and pain medications that became quite severe during her breast reconstruction surgery, resulting in a collapsed lung. She struggled with agonizing nerve pain throughout her recovery.

“It took a tremendous toll on my body,” recalls Janice. “I wasn’t taking care of myself, and I wasn’t sleeping well.” Then her thyroid stopped working properly, and she began gaining weight.

“I was so tired and miserable, and then I saw information about the COIN study,” she says.

Janice’s sleep problems required more intervention. Medical exams and tests done as part of the screening for patients who wanted to begin the COIN study revealed she had obstructive

sleep apnea and was waking up 130 times a night.

“I knew I wasn’t sleeping well. I had no idea it was that bad,” Janice says.

Successful treatment of her sleep apnea was required before she could begin the COIN study. Even with the apnea under control, however, Janice was still waking up at night when she entered the sleep portion of the COIN study.

“I learned how to observe my body and feelings, and began to recognize how caffeine and how I was eating affected my sleep,” she says.

With treatment and guidance that helped both women with their individual challenges, Jennifer and Janice successfully completed the sleep portion of the study. With their insomnia and sleep disturbances abated, they moved on to the weight loss part of the study.

With the help of a weight loss coach, both women installed an app on their phones to track daily dietary selections, calories, exercise minutes and weekly weight. The COIN study used **Under Armour’s My Fitness Pal**, but Coughlin says there are other apps that work similarly. The weight loss program provided goals for daily calories and for exercise—180 minutes of aerobic activity per week, and health coaching helped with personalized weekly goals. Jennifer, for example, focused on limiting sugar and salt.

“Tracking is a tool we use to keep participants engaged in behavior change, which is essentially eating less, eating healthily and moving more,” says Coughlin. “It helps measure change and develop insight, motivation and awareness.”

Janice says she noticed right away that she had been eating many more calories than she thought. In the past, she tried other popular diets that count points or require participants to eat specific foods. They never worked for her, she says, because they were too restrictive and required her to eat meals different from what she was cooking for the rest of her family.

“COIN was different,” Janice says. “I was finally ready to take care of myself. I was committed to this. I had to own it. I was the one in control, but

things that interfere with it to help her develop better sleep habits.

It was difficult at first, Jennifer says, but in about a month, she describes feeling like her body rebooted. Now, she was able to get high-quality sleep at night, so she felt rested and had more energy during the day.

Patients often feel tired during the day because they do not get high-quality sleep at night. They may be in bed, but they are tossing and turning and not getting the restorative sleep their bodies need, explains Coughlin.

“When I was going through chemotherapy before my surgery, everything else went by the wayside. You eat when you can eat and sleep when you can sleep,” says Jennifer.

Her emotional roller coaster began with no warning at age 47. Still reeling from her breast cancer diagnosis, Jennifer searched the internet to find information. Based on what she read, she remembers thinking, “I’ll be OK as long as it’s not triple negative.” When the results of her biopsy came back, her

my coach gave me the help and encouragement I needed to get that control.”

Amanda Montanari has been a weight loss coach for the COIN study for over a year. “It’s been the best experience of my career,” she says. The program is individualized, helping participants learn what works best for them by tracking everything they eat, their exercise and their weight. The ultimate goal is 10% weight loss by sustaining healthy, lifestyle choices.

“Some hit their goals sooner than others. By the end of the program, my hope is that they learn they can do this by themselves. We want them to connect with feeling better so they don’t want to lose that feeling,” says Montanari. “A diagnosis of cancer is no small thing. We want to help them put themselves back in the driver seat so that now, as a survivor, they have the skills to make lasting change.”

The six-month program — which Coughlin stresses is a lifestyle change, not a diet — begins with 12 weekly coaching sessions. It then moves to monthly sessions aimed at helping participants reduce foods that are not heart healthy and conversely add foods that are, and offers ways to introduce moderate to vigorous exercise in their daily routines. Coaches help partici-

pants navigate things like social gatherings, weekends, holidays and special occasions that might result in the temptation to overeat. Participants talk about things that are going well and talk about strategies for overcoming obstacles, such as stress eating. They are also given educational materials to support their weight loss journey.

When tracking calories on the app, Montanari encourages participants to be honest with themselves. “I reassure them that I’m not going to judge them, but if they don’t log it, it’s difficult for us to find patterns that could be sabotaging their progress and making it hard for them to learn,” she says.

Even if a participant feels like they had a bad week, there are always successes to point to, she says. Montanari is intrigued by the psychology of weight loss. As a cancer survivor herself, she was grateful for the opportunity to work with others in the same situation.

“It’s been amazing to work with these women. What they’ve gone through as cancer survivors and their commitment to COIN is inspiring,” says Montanari.

Jennifer liked that the app kept her accountable. It helped her with portion control and to think more about what she was eating, and she began to make healthier choices. When she had setbacks, her coach was not judgmental. Instead, her coach helped her get back on track and find ways to cope with stress or life events that can sabotage healthy eating.

Jennifer is amazed at how far she’s come. She reflects on a photo taken when she visited her daughter at college for parents’ weekend.

“It was horrible. I could hardly walk. Now, my daughter and I are walking 5Ks together,” she says. She set running a half-marathon next year as one of her goals. Jennifer stresses: “It’s not about getting skinny. It’s about getting healthy.”

Janice has similar thoughts, recalling a time when she dreaded exercising and couldn’t walk up a hill without stopping to rest. “I pushed to get through 20 minutes, and now I love my hour of walking,” she says. “My coach helped me make myself a priority. Without that, there is always an excuse.”

During their weight loss journeys, both women faced several challenges. COVID-19 hit, and gyms closed, so Jennifer ordered weights and other gear for home-based workouts. Then her father passed away.

“I was trying to do this, but I felt like everything was coming down on me,” says Jennifer.

Janice had similar experiences, facing COVID-19 and a death and serious illness in her family.

“I think I would have been on a track to become heavier, if I had not been in the COIN program during COVID-19 and these life changes,” says Janice. “When I had a bad time or week, my coach was encouraging. It was important to have someone to talk to help guide me and navigate through these things.”

Although Janice and Jennifer are at different places in the COIN study and have different weight loss goals, they are both seeing success.

Janice is still in the study. “With everything going on, I am down 22 pounds and still on track,” she says. “I was in a bad place. The study allows me to work on me and move forward. I feel blessed to be a survivor, but I wasn’t living like one. COIN has helped me so much, and I’m proud of what I’ve accomplished.”

Jennifer completed the study and says she feels better than she has in years. She lost 57 pounds and says she’s maintained her healthy lifestyle and continues to lose weight.

“I have the tools now, so I’ll be OK,” Jennifer says. “There is no way I’d be where I am without the COIN program. I’m so thankful.”

**More on the Web:**  
**Remote Coaching Can Help Breast Cancer Survivors Achieve Healthy Weight Loss** <http://bit.ly/2ZPOWER>



# THE PROMISE OF IMMUNOTHERAPY

## Bringing Immunotherapy to Patients with Breast Cancer

IMMUNOTHERAPY IS ONE of the most promising new cancer treatments, as it can turn the power of the immune system — more powerful than any cancer drug — against cancer cells. In some cancers, like lung cancer and melanoma skin cancer, immunotherapy has been successful at treating even advanced cancers. Responses in breast cancer have been more limited, so it has been challenging to move forward with immunotherapy studies, but experts like **Cesar Santa-Maria, M.D., M.S.C.I.**, are not giving up. He is exploring ways to make breast cancer an immunotherapy-responsive cancer, investigating drug combinations and identifying biomarkers that flag cancers most likely to respond.

Two large national studies, Impassion130 and KEYNOTE 355, studied the benefit of combining chemotherapy with anti-PD-L1 and anti-PD-1 inhibitors in hundreds of patients with metastatic triple negative breast cancer. The PD-L1/PD-1 receptors are immune checkpoints, controlling an “on/off” switch of sorts that cancers often exploit to shut down the immune response to tumors. Drugs that block PD-L1 and PD-1 can unleash these restraints, causing immune cells to attack cancer. In both of these studies, Santa-Maria says they found that patients whose cancers expressed high levels of PD-L1 had improved, progression-free survival.

“We eagerly await mature overall survival data, but these results suggest we may be heading in the right direction,” he says.

Santa-Maria says the importance of biomarkers in selecting patients for treatment with immunotherapy is becoming clearer with research. Tumor mutational



burden, or the quantity of genetic defects in the tumor, is one such promising biomarker, he says.

Tumors with large numbers of genetic mutations stand out to the immune system because these alterations to DNA can result in abnormal, cancer-specific proteins that the immune system can recognize. Only about 3% to 4% of breast cancers have high levels of mutations (classified as tumor mutational burden higher than 10 mutations per megabase), says Santa-Maria, and that’s why biomarkers are so important to guide the right patients — those likely to respond — to immunotherapy.

“We are learning how to use these biomarkers and looking for new ones that point to who will benefit from immunotherapy and what combinations of drugs will work best,” he says.

Santa-Maria and a group of clinical scientists are heading the Patient Response to Immunotherapy using Spliceosome Mutational Markers (PRISMM) study, which will investigate a cellular feature that works similarly to tumor mutational burden to attract the immune system to cancers. It focuses on a type of RNA editing cellular machinery that influences protein production, called the spliceosome. Santa-Maria says rare mutations to the spliceosome cause variations in protein production that should make the cancer look unusual enough to the immune system to

draw a response. They are studying whether treating these patients with immunotherapy will cause their immune systems to attack their cancers.

The PRISMM study has a unique virtual design and will soon open to advanced breast cancer patients being treated by an oncologist anywhere in the mainland U.S. Patients who had genetic studies of their tumors (sequencing) that revealed a spliceosome mutation may participate. All treatment will take place with their local oncologists, with Johns Hopkins researchers providing treatment recommendations through a specialized molecular tumor board and remote follow-up. Information about the study will go out to the public via social media campaigns and postings on disease-specific discussion groups and websites.

“This represents a first but critical step toward making personalized, precision medicine available to the larger public and also enabling rare mutations to be studied at scale,” says Santa-Maria. “It also takes a key first step toward incorporating outcomes in the community setting, where most cancer patients receive their care, into the body of academic literature and knowledge.”

The INDALA (Immunopharmacodynamic Study of Neoadjuvant Durvalumab Alone or in Combination with AZD4635 in Triple Negative Breast Cancer) study is a collaboration among heavy hitters in cancer research and immunotherapy. Nobel Prize winner **Gregg Semenza, M.D., Ph.D.**; leading cancer immunology expert and Kimmel Cancer Center Deputy Director **Elizabeth Jaffee, M.D.**; and **Jonathan Powell, M.D., Ph.D.**, Associate Director of the Bloomberg-Kimmel Institute for Cancer Immunotherapy, are exploring how targeting adenosine receptors could enhance responses to immunotherapy. Adenosine is a metabolic byproduct that can “switch off” cancer-attacking immune T cells. Santa-Maria will be conducting a clinical trial in patients with early-stage (stage 1 to 3) triple negative breast cancer to evaluate how to overcome this potential resistance mechanism to immunotherapy. The study is expected to begin in early 2021.

# MEET OUR NEW NAVIGATORS

## Helping Guide Patients Through Diagnosis, Treatment and Survivorship

**Yolanda Bennett,**  
*Surgery Navigator*

Yolanda Bennett joined our navigator team in July. A breast cancer survivor herself, she supports newly diagnosed breast cancer patients work through the treatment options presented by their surgeon—choosing between lumpectomy or mastectomy, for example—so they can prioritize their goals and decide the course of treatment best suited to their individual needs and wishes. She also helps patients overcome barriers to care, including guiding them to financial resources, helping with transportation or insurance issues. Contact Yolanda at [ybennet2@jh.edu](mailto:ybennet2@jh.edu).



**Kate Pisano,**  
*Women's Wellness and Healthy Aging Program Navigator*

Breast cancer survivor and former patient liaison Kate Pisano is the navigator of the new Women's Wellness and Healthy Aging Program. Specialists from several departments educate, treat, and advocate for women transitioning to menopause and women who are young breast cancer survivors experiencing symptoms of menopause. Kate speaks with patients and doctors to understand needs and facilitate consultations with the appropriate specialists. The goal is healthy aging after breast cancer through intervention to prevent and manage health concerns. Contact Kate at [womenswellness@jhmi.edu](mailto:womenswellness@jhmi.edu).



Read more about our breast cancer navigators at <http://bit.ly/KimmelNavigators>

## The John Fetting Fund for Breast Cancer Prevention



This video was made before the COVID-19 pandemic

## IMAGINING A WORLD WITHOUT BREAST CANCER

Learn more and watch our new video at: <http://bit.ly/fettingfund>

# EVENT ROUNDUP

## Upcoming

All events are **FREE** and open to all breast cancer survivors, thrivers, and caregivers unless otherwise noted.

### Yoga Therapy Webinar

October 14, 2020. 7 – 8 pm ET

Amy Genevieve Kozak is a Kripalu yoga teacher, an internationally certified integrative yoga therapist, and a Duke Integrative Medicine-trained and national board-certified integrative health coach.

Yoga therapy is the process of empowering individuals to progress toward improved health and well-being through the application of the teachings and practices of yoga. This webinar is intended to provide tools that may improve physical functioning, reduce fatigue, minimize stress, enhance sleep and strengthen overall quality of life.

### Integrative Medicine as a Road to Self-Healing in Cancer Webinar

November 9, 2020, 3 pm ET

Dr. Rosanne Sheinberg is an Assistant Professor of anesthesiology and critical care medicine at the Johns Hopkins University School of Medicine and the Director of the Johns Hopkins Integrative Medicine Program.

Integrative medicine can help minimize the side effects of cancer treatment, improve quality of life in survivorship and reduce the rate of recurrent disease. During this webinar, we will discuss lifestyle pillars that can aid in epigenetic changes, ways to reduce inflammatory markers and tips to improve immune system function, including nutrition, exercise, stress, sleep and environment.

**To see our schedule or to register for any of our upcoming live webinars, visit <https://bit.ly/31Wk5OW>.**

### The Feldenkrais Method®

December 10, 2020, 3 pm ET

The Feldenkrais Method® of somatic education uses gentle movement and directed attention to help people learn

new and more effective ways to increase ease and range of motion, improve flexibility and coordination, and rediscover innate capacity for graceful, efficient movement.

Stacia Lee Gallagher is a former high school English teacher and cancer survivor and a Guild Certified Feldenkrais Practitioner, Pilates trainer and Cancer Exercise Specialist, working in the movement and education industries for more than 34 years.

Note: All events are free, but preregistration is required.

### Prerecorded content

Listen to a recording of our latest webinar on mindfulness for stress reduction and well-being. To listen to this or other recently recorded webinars, visit <https://bit.ly/31UlwNI>.

## Help Us Make a Difference

Each contribution to the Johns Hopkins Kimmel Cancer Center makes a difference in the lives of cancer patients here at Johns Hopkins and around the world.

Our physician-scientists are leading the way on many of the scientific breakthroughs in cancer, and your donation will support patient care and innovative research that is translated to better, more effective treatments. We are also focusing on ways to prevent cancer and support survivors.

You may designate a gift to a specific faculty member.

**To make your donation online** [hopkinscancer.org](http://hopkinscancer.org) and click “Make A Gift”

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Johns Hopkins Kimmel Cancer Center  
750 E. Pratt St., Suite 1700  
Baltimore, MD 21202

### To contact our Development Office

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