The stories and statistics behind breast cancer

Survivors and their loved ones open up about treatments and challenges they've faced while fighting breast cancer.

At a routine checkup, Lee Gordon's doctor noticed a lump but said she thought it was likely a cyst. To be sure, Lee was sent for a mammogram. Then a biopsy. Then a second mammogram. A week later, Lee got the diagnosis: Stage 2 breast cancer with some involvement of the lymph nodes.

Because Lee is of Eastern European Jewish descent, genetic testing for the BRCA (BReast CAncer) gene was also recommended because of a higher risk for other forms of cancer, but only a slim likelihood of a breast cancer recurrence. Luckily, Lee was not a carrier.

As volunteer services manager for an organization providing end-of-life services, Lee is no stranger to death and dying. Lee says sitting in on hospice team meetings, "was a strong dose of reality, seeing someone my age with a terminal cancer diagnosis. I

thought: 'There but for the grace of God go I.'" While support groups weren't Lee's thing, Lee sees their value, having helped facilitate them through work.

Many breast cancer patients do seek out support groups to combat the isolation they feel. Loneliness was a big issue for Lee. "I was the only man in the waiting room. It was a little awkward," he admits. Undergoing treatment during COVID compounded Lee's sense of aloneness. For men, the lifetime risk of getting breast cancer is about 1 in 833, versus one in eight for women, according to Breastcancer.org. According to the American Society for Clinical Oncology (ASCO), the current five-year survival rate for men with breast cancer is 84%.

To other men facing a breast cancer diagnosis, he advises: "Don't be ashamed about it." He also says it's important to have a doctor you can trust — one who's empathetic, supportive, and frank, but not condescending. "If you're going to talk at me, forget about it. If you don't have that, find somebody else."

BRCA drug facts

- In the drug pipeline for HR+/HER2- breast cancer are agents called PARP inhibitors, which prevent DNA repair within the cancer cell, eventually resulting in the cell dying. One major drawback is that they have so far generally been effective only in patients with a certain mutation, called a BRCA1/2 mutation. This makes up only about 10-15% of breast cancer patients.
- Two PARP inhibitors approved for HER2- breast cancer, Lynparza and Talzenna, have had significant success in the patient segment with correct BRCA-mutated patients.

Source: Datamonitor Healthcare

Two-time cancer survivor turned advocate

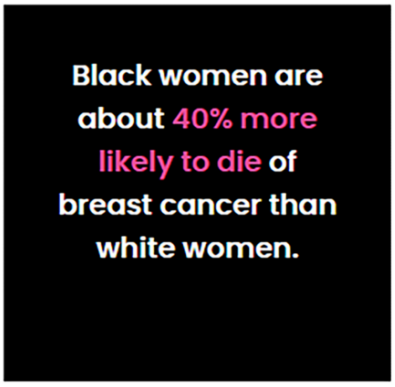
That's exactly what patient-turned-advocate Kimberly Richardson did. She is a survivor of ovarian cancer and early stage, triple-positive breast cancer. In addition to serving on various advisory boards, she has established a special commission on gynecologic cancer in the state of Illinois and is the 2021 recipient of the National Coalition for Cancer Survivorship's Ellen L. Stovall Award for Patient Innovation in Cancer Care.

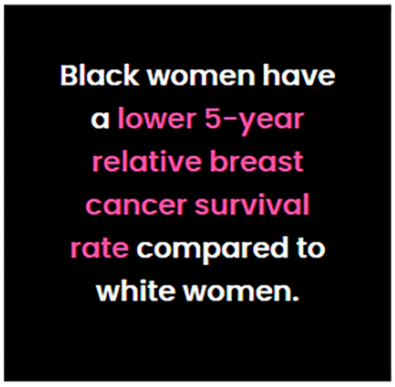
After her ovarian cancer diagnosis in 2013 and a "tumultuous relationship" with her oncologist, when she was diagnosed with triple-positive breast cancer in 2020, she says, "I wasn't going to take any crap off anybody." She demanded a genetics test and that her previous tumor be tested against the new one to determine if the cancer had spread or was unrelated. It turned out to be the latter. "I was leading the discussion…. The ultimate decision was going to be mine" whether to have a lumpectomy versus a mastectomy. She opted for a lumpectomy.

Like Lee Gordon, Kimberly was coping with both cancer and COVID. When an intake nurse at the infusion center asked if she had any of the following symptoms — runny nose, scratchy throat, or cough (the same symptoms caused Herceptin, used in her treatment) — and she answered "yes," she was immediately put in isolation, but never tested for COVID.

Finally, toward the end of Kimberly's chemotherapy doctors gave her the green light to get the COVID vaccine. Three days later, she contracted a mild case of COVID. A nurse promptly called her — assuming that she was misguided or miseducated — to confirm that COVID was not a conspiracy. She did *not* receive a call, however, to confirm her chemo appointment scheduled 10 days later. "They left me hanging," she says. "You have to treat everyone as individual human beings." She adds that healthcare organizations must check who they are hiring, be on the lookout for implicit bias, and train for cultural competency.

It is important to note that, as across disease states, there are racial disparities in breast cancer survival rates. Many of the presentations at the American Society of Clinical Oncology (ASCO) 2022 convention focused on these issues.





A 2020 paper from the National Institutes of Health found white women in the US

have a 5-year survival rate of 92% compared to 81% for Black women. The paper also found Black women are less likely to get breast cancer but more likely to die from it.

The Susan G. Komen Foundation has released landscape analyses, "Closing the Breast Cancer Gap: A Roadmap to Save the Lives of Black Women in America," examining 10 metropolitan areas — Atlanta, Chicago, Dallas, Houston, Los Angeles, Memphis, Philadelphia, St. Louis, Tidewater VA, and Washington DC — to understand the unique drivers of disparities in each community. The reports identified several trends that exist to varying degrees in each area.

In response to the report's findings, Komen is launching "Stand for H.E.R. — a Health Equity Revolution," a focused initiative to decrease breast cancer disparities in the Black community by 25 percent beginning in the U.S. metropolitan areas where inequalities are greatest.

A year ago, Kimberly founded the Black Cancer Collaborative, a nonprofit organization that creates partnerships between Black cancer patients and the medical and scientific communities on issues of health equity, patient inclusion and clinical trial participation. She formed the organization due to high rates of Black mortality in screenable, treatable cancers: "Yet Black women are dying," she says. Her mission is to build the capacity of Black patients and their caregivers, and to facilitate conversations in the medical and science communities. You can find Kimberly on Twitter and LinkedIn.

Brynne Rhodes and her mother, Kim, strike a "Flash the Ribbon" pose

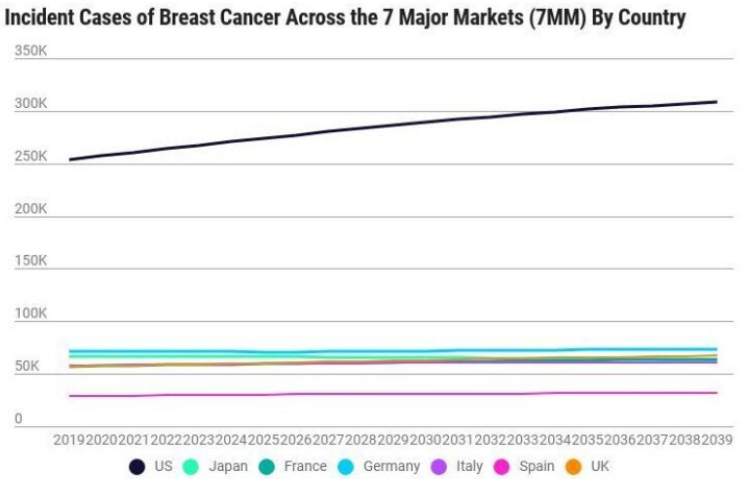
A family of advocates

When life gives you breast cancer, make lemonade. Pink lemonade, that is. Brynne Rhodes was only 7 when her mother, Kim, was diagnosed with Stage 2 breast cancer.

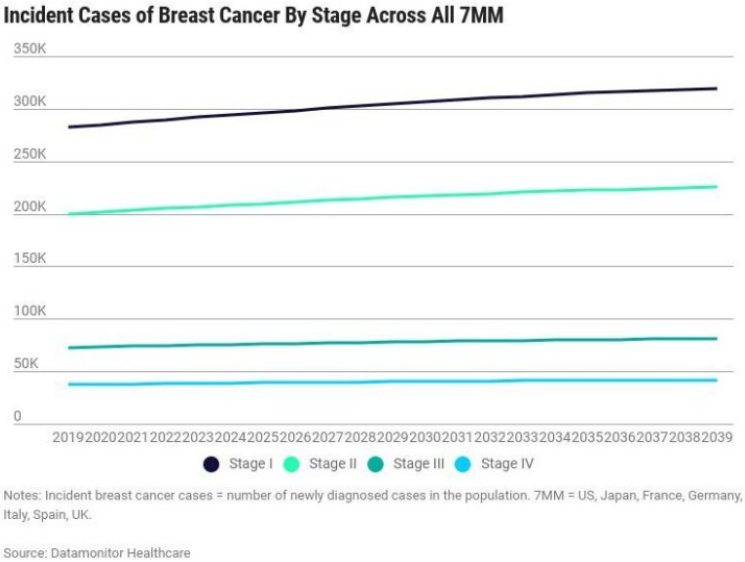
Brynne decided to hold a lemonade stand to raise money to help find a cure for breast cancer. Her first stand raised over $100. Word of the Pink Lemonade Stand Challenge quickly spread to 15 states, raising $1,000. In 2019, Brynne and her mom were featured on the "Today" show. To date, the challenge has reached 37 states and raised more than $112,000. All funds raised go to the Breast Cancer Research Foundation (BCRF).

Brynne, now 12, speaks with the poise and passion of someone much older. "It's not all about the money," she says, adding that education is important, too. She encourages people of all ages to accept the challenge and set up a pink lemonade stand. Their project is a family effort; Kim's oldest son built their website, and another son produced the challenge's official video.

Kim's mother, sister, grandmother, and even mother-in-law have all fought the disease. Even with Kim's family history, her doctor did not recommend annual mammograms until Kim turned 35. Her breast cancer went undetected for seven years.



Like about [45% of women](), Kim has dense breast tissue. Because of that, she had ultrasounds in addition to her regular mammograms, but they did not pick up her cancer either. “I did not have MRIs, and I wish in hindsight that I did,” Kim says. “You have to self-advocate. You have to ask for an MRI. You have to be insistent.” She notes that it’s usually not until after a woman is diagnosed with breast cancer that an MRI is ordered. She says one reason she didn’t have routine MRIs is because she didn’t want to fight with her insurance company; an MRI may or may not be covered by insurance, depending on the insurance company and policy.



Kim happens to be the aunt of Aubrey Syrek, a renewal specialist at Citeline, and whose mother was diagnosed in May with breast cancer. Although her mother had yearly mammograms, her breast cancer was not detected until it was of a size that could be seen. Aubrey says that working in the pharmaceutical industry is so fulfilling. "Citeline puts an importance on education and makes sure information is accessible. We really care. We go above and beyond. It's so uplifting."

As the statistics above indicate, breast cancer is projected to increase in the U.S., as well as all stages of the disease.

> *"I have a burning passion to put an end to breast cancer so the next generation doesn't have to face it." – Kim Rhodes*

Her passion is her purpose

While Helene Fisher received conflicting advice regarding treatment, one thing was certain. She had breast cancer. She was 66, the same age as when her mother was diagnosed. In fact, she remembers the exact date and time of her diagnosis: 2 p.m. Friday, Dec. 16, 2016. "I heard the words 'a year of chemo'" she says, and she immediately started researching so that she could make informed decisions about her care. "By Monday morning, 'I could have taught a course on the topic.'"

Helene was diagnosed with HER2+ breast cancer, a mutation. There are three main types of breast cancer: HER2+, HR+/HER2-/hormone receptor+, and triple-negative breast cancer (TNBC), and each is treated differently. She is passionate about educating and advocating for other women with HER+ breast cancer. She devotes hours daily as volunteer moderator of a Facebook support group for women on hormone therapy. Its ranks have grown to more than 10,000 members.

Helene Fisher, moderator of Facebook group for women on hormone therapy for breast cancer

After a biopsy, her doctor did a lumpectomy in order to acquire a bigger sample to send to two labs. Doctors were still in disagreement about the course of treatment, so Helene called her cousin, a doctor, who said “Pathology is an art, not a science.”

She got a second opinion and recommends that others diagnosed with breast cancer do so. She emphasizes that patients don’t have to travel for a second opinion. They can use Zoom or visit a research facility’s website and click on a “second opinion” link.

Her sample slides were sent to Memorial Sloan Kettering Cancer Center, which took her case to the tumor board. “I didn’t know you could do that,” she says. New York’s Sloan Kettering and Boston’s Dana-Farber/Brigham and Women’s Cancer Center are among the top five hospitals ranked for cancer treatment by the *U.S. News & World Report*.

Sloan Kettering totally disagreed with the first opinion, that she had non-invasive ductal carcinoma in situ (DCIS). DCIS tumors, the earliest form of breast cancer and not requiring chemotherapy, have some characteristics of invasive cancers but have not penetrated the mammary duct or the breast supportive tissue. In the end, she decided

on a more aggressive treatment but on “chemo lite” (one chemo drug and one targeted therapy drug as opposed to two of each, which was deemed overtreatment).

While Helene did get two opinions, she says, “You have to trust your doctors. You don’t get your degree from Google university. You really have to trust their experience.”

Helene was on the chemotherapy drug doxorubicin (Adriamycin), also known as The Red Devil (because the color of your urine is red while you’re taking it) for one year. During that time, she had to have an echocardiogram every four months to ensure her heart health, as doxorubicin can be associated with heart toxicity. She also was on the targeted therapy drug Herceptin every three weeks for one year. Today, she remains on a generic hormone blocker, and notes that it is very difficult to get insurance to pay for a brand-name drug.

She admits she was terrified about undergoing chemo but, to her surprise, “It was the best day of the week. It was spa day.” She brought a comfy quilt, cozy slippers, and binge-watched Netflix on her iPad.

HER2+ drug facts

- Herceptin targets a receptor called HER2. Targeting HER2 in HER2+ breast cancer has been shown to be extremely effective and almost all of the approved drugs in the metastatic setting also target HER2 in some way.
- In the last decades, the drugs primarily used to treat HER2+ breast cancer were antibodies; Herceptin is an antibody, and there are many other HER2-targeted antibodies widely used such as Perjeta.
- In HER2+ breast cancer, Herceptin has been the favored treatment since the '90s. Although drug manufacturers are still trying to develop better drugs for this breast cancer subtype, it has been difficult to beat Herceptin despite newer technology and research.
- One up-and-coming drug in HER2+ breast cancer is Enhertu, which has the same target as Herceptin but has an added punch as it also delivers chemotherapy directly to the breast cancer cell. It is approved for pretreated metastatic HER2+ breast cancer patients but is slowly gaining approval earlier and earlier in the HER2+ breast cancer patient journey. ADC (antibody-drug conjugate) Kadcyla also is receiving increasingly widespread use.
- There are a lot more drugs in the HR+/HER2- breast cancer pipeline compared to the HER2+ pipeline, and this is because HR+/HER2- breast cancer doesn't have one single drug which is as well-established as Herceptin. Furthermore, as this type of breast cancer is HER2-, meaning there is little or no HER2 expressed on the breast cancer cell, there are a wider range of targets that drug manufacturers can look at to target the cancer.

Source: Datamonitor Healthcare

Helene opted for a lumpectomy, noting that, with radiation, it has been proven to be as effective as a mastectomy. She also notes that more mastectomies are conducted in rural areas because many patients can't travel far to receive radiation treatments. This 2020 paper found that living in a more rural area was associated with increased mastectomy rates (53.4% rural patients received mastectomy of any kind versus 49.3% in large metropolitan areas).

She says there is a great deal of misconception about both mastectomy and radiation, adding that the latter does not cause secondary cancers as it did in the past. She went every day for 20 sessions. "I looked so healthy," she says, and felt healthy, too. "I went to Zumba!"

Sharing her story, one class at a time

For Marianne Martino-Giosa**,** Zumba was — and is — a lifeline. Diagnosed with hard-to-treat, triple-negative breast cancer (TNBC), the Zumba instructor credits being in shape with her good outcome. She's now back teaching Zumba, and attended the national Zumba Instructor Convention, which was her personal goal throughout treatment.

She describes TNBC as the worst type of breast cancer, because it does not typically respond to any currently available treatments. Marianne enrolled in a clinical trial to test a new treatment protocol. Instead of receiving eight treatments, four adriamycin/cyclophosphamide (AC) and four with Taxol/carboplatin, she was to undergo 12 treatments, adding the recently approved Keytruda, already used to treat multiple other cancers. However, Marianne says when she got to treatment number nine, “My body said that was enough.” She was hospitalized, as her body rejected the drug mix and went septic. The good news is that a mammogram revealed she was already breast cancer free. She then had a lumpectomy to remove the damaged tissue.

During her treatment, Marianne never got sick. “I walked three miles every day,” she says proudly. Her doctors said one of the main reasons she responded so well to the

treatment was because she is so healthy, even though cancer runs in both sides of her family.

> *"I've never smoked a day in my life, I've never taken a drug, I eat a relatively healthy diet, I've been a fitness instructor for umpteen years. I was so surprised. My doctor explained, 'You don't choose cancer, cancer chooses you. Cancer doesn't discriminate.'" – Marianne Martino-Giosa*

Marianne was very public about her breast cancer journey, posting her progress on Facebook. The petite dynamo is a role model and inspiration for many. At the beginning of each Zumba class, she shares wisdom from her experience.

"You always live in fear of cancer. But I embrace the journey."

TNBC drug facts

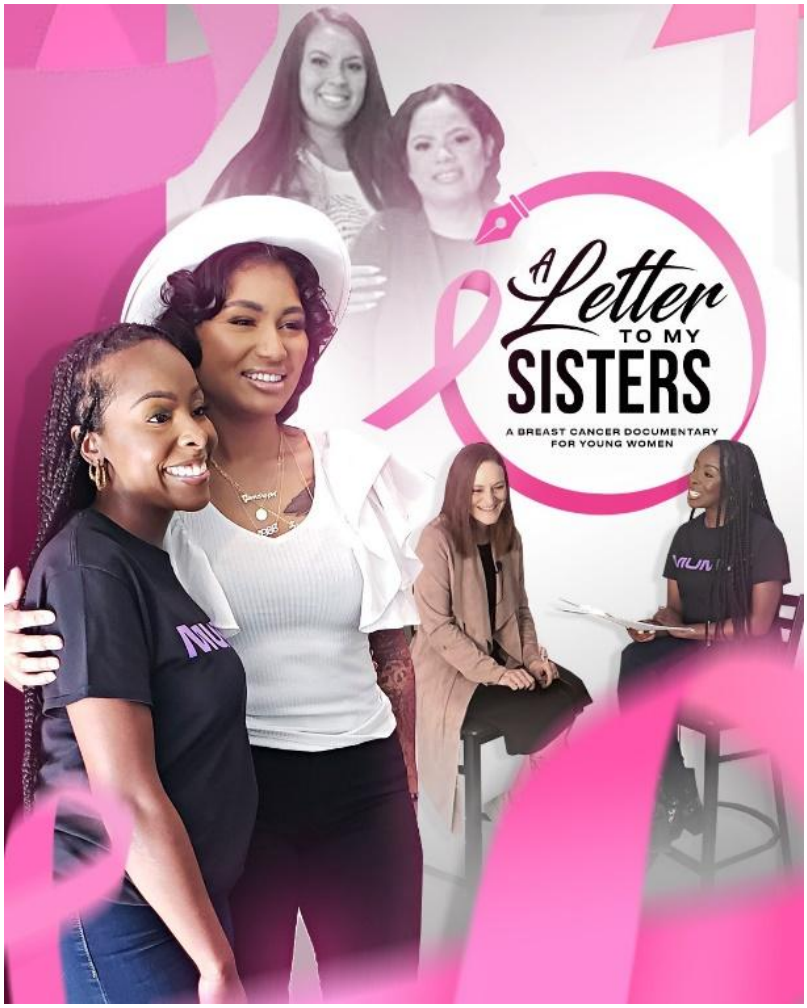
- Keytruda is approved for metastatic patients and is one of the first targeted agents to make a real difference for TNBC patients.
- In the pipeline, there are two types of drugs called PI3K inhibitors (Piqray and capivasertib). Within the cell, there are proteins called PI3 kinases (PI3Ks) which lead to growth and survival of the cancer. PI3K inhibitors aim to prevent the growth and survival occurring in the cancer.
- However, the problem with these agents is that they are not good at distinguishing between cancer cells and regular cells, which can lead to significant side effects. Nonetheless, as there are so few options for TNBC patients, they may still be used if approved.
- An ADC called Trodelvy is receiving widespread use in late-line metastatic TNBC, and it is expected that ADCs will become a firmly established part of the treatment paradigm.
- In TNBC there were extremely limited options, with most patients being treated with standard chemotherapies, and prognosis was very poor. Immunotherapies are making inroads, but they are limited to people with certain biomarkers, and have not yet been shown to be effective in the total population, although this may change in the future.

Source: Datamonitor Healthcare

Radiation therapist turned documentary filmmaker

Dr. Nia Imani Bailey, DPA, M.A.Ed, RT(T), is a radiation therapist whose patients-turned-friends inspired her to produce a documentary on breast cancer in women age 40 and younger. "I would always see young women coming in for breast cancer

treatments," she explains. "It wasn't until they passed away that I said, 'What is going on?'"



In October, she held the premiere of her film, "A Letter To My Sisters: A Breast Cancer Documentary For Young Women," produced by DayDream Kreative Studios. The film offers insight into the journey of three diverse young women dealing with their breast cancer diagnosis and life itself, while also highlighting prevention measures.

Her doctoral degree is in public administration, but her passion was — and remains — breast cancer. Her doctoral dissertation, "Federal Health Reform: Breast Cancer Outcomes," focused on how young women are not only diagnosed with breast cancer, but are dying from breast cancer. She sought to prove the significance of lowering the mammography age from age 40 to 30, examining policy frameworks of screening mammograms and insurance coverage. She cites as an example colonoscopy exams,

which the American Cancer Society first recommended at age 50 but changed to 45.

She also is advocating for 3-D mammography MRIs for women with dense breasts, which may not be covered by insurance. According to DenseBreast-info.org, "dense breasts" describe the mix of fat, milk glands/ducts and fibrous tissue in a breast. The more glands and fibrous tissue, the denser the breast. The website explains that because both dense tissue and cancer show up as white on a mammogram, detecting cancer "is like trying to see a snowball in a blizzard." Dr. Bailey also notes that insurance does not cover genetic testing, which costs an average of $200.

"Information is power," she says, and shares some breast cancer statistics from her 2020 dissertation:

- The incidence rate for female breast cancer in the U.S. from 2010 to 2014 was 123.6 per 100,000 population
- A total of 2,423,875 women were diagnosed with breast cancer between 2004 and 2015
- 136,525 breast cancer patients were younger than 40 years old
- 82% of breast cancers are diagnosed among women 50 or younger, with 90% of breast cancer deaths in this age group

She encourages those interested in breast cancer reforms to sign petitions and contact their insurance company, local government and other organizations.

What does the filmmaker hope women will take away from her documentary? "Simply know your body."

A constant reminder of her breast cancer

Some breast cancer survivors, like Teresa (not her real name), live with a constant reminder of the disease. She not only opted to undergo a bilateral mastectomy, she permanently lost her hair. "But, it's not cancer," she's quick to say. "So I count my blessings. It's a nuisance."

Teresa was on the chemotherapy drug Taxotere (docetaxel), which has been associated with this lasting side effect. She says other drugs such as Taxol are now used to treat her

type of cancer, invasive ductal carcinoma (IDC), the most common type of breast cancer.

Although the use of cooling caps was recommended to avoid hair loss, Teresa did not use them. She says that after her initial hair loss, “I was waiting for my hair to grow back, impatiently. It started. And when it did, it was white stubs.” She compares it to male-pattern baldness.

She has spent the last decade trying to deal with her hair loss. She has both a full wig as well as a topper that clips on and blends with her remaining hair. “It’s challenging,” she says matter-of-factly. “Especially if it’s a gusty or hot day.”

Teresa’s wife has been extremely empathetic and protective throughout her ordeal, which began 11 years ago. “She was extremely quick to do the research,” Teresa says.

Receiving information related to one’s treatment is one thing; *how* it is delivered is quite another. Teresa had reconstructive surgery following her mastectomy and remembers the language her plastic surgeon used to describe the procedure. “He said, ‘I could shove some 430s in there,’” referring to the size in cubic centimeters of the implant. “He lost me right there.”

Living with lymphedema

Like Teresa, Maryjane Finne only needs to glance at the compression sleeve on her arm to be reminded of her 2002 bout with breast cancer. While she has had no recurrence osince her diagnosis, Maryjane says she has adopted “a modified ostrich approach. You stick your head in the sand but look up every once in a while to make sure you’re OK.”

After a routine mammography revealed an abnormality and a follow-up sonogram, Maryjane’s doctors decided her tumor was small enough to do a lumpectomy. She had a sentinel node biopsy, which at the time was a new procedure.

A writer, Maryjane has done considerable research on the procedure and explains that there are 15 to 30 lymph nodes in a person’s armpits. If breast cancer spreads to the lymph nodes, it is in a particular order. Dye is injected into each node as needed; only

the cancerous nodes need to be removed. She had eight nodes removed. “It was quite a bizarre thing. I had to hug what seemed like a gigantic refrigerator and stand there with my breast pressed against it.”

She emphasizes that her tumor was very small. No chemotherapy was needed because she had “clean margins,” meaning there were no cancer cells at the outer edge of the cancerous tissue that was removed. She did, however, require radiation.

Everything was fine for two years. “I just went on with my life,” she says. Then she woke up one morning and her hand was swollen, knuckles dimpled. Maryjane says she knew it was lymphedema right away because she saw a friend go through it. She received both physical therapy and occupational therapy, and her arm was wrapped 24/7 with thin foam rubber sheets and ace bandages.

> *“I looked like the Michelin man.” – Maryjane Finne*

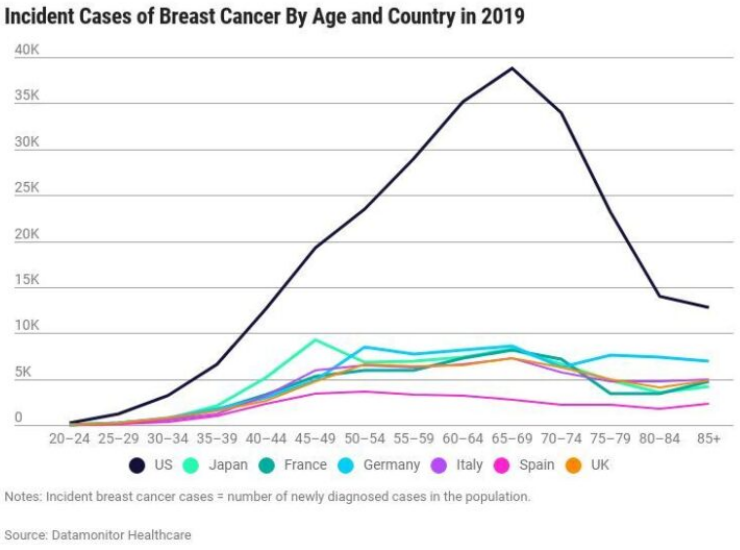
Maryjane still must constantly wear a compression sleeve, except when sleeping “and maybe special occasions,” she adds. It wasn’t her first experience wearing one. Due to a previous burn on her hand, she had to wear one for six weeks. This time, though, it’s forever. She wears it religiously, as she is predisposed to contracting cellulitis, a serious infection of the skin that could lead to sepsis and even death. “You’re always on the edge,” she says. “My arm gets red and hot.”

Patients are recommended to change sleeves every six month, but she does so every year because each one costs over $100 and her insurance doesn’t cover it.

While she was shopping recently, a woman saw her sleeve and asked her for a referral. Maryjane was happy to help, especially because English was not the woman’s first language.

Trends in the breast cancer landscape

According to Citeline research, the top 10 pharmaceutical companies in 2021 by revenue are as follows: Pfizer, AbbVie, Johnson & Johnson (J&J), Novartis, Roche, Bristol Myers Squibb, Merck & Co., Sanofi, and AstraZeneca. All with the exception of J&J have at least one agent either approved or in the pipeline for some form of breast cancer.



The age group with the highest incidence of breast cancer (for 2019) varies across countries. In the US it was ages 75-79; in Japan 60-64; in France, Italy and Germany 65-69, in Spain 80-84; and in the UK 85+.

From 2011 to 2017, the five-year survival rate for female breast cancer in the US was 90% (for all stages combined). As new treatments are developed, the survival rate can be expected to continue to climb. And, from the personal stories shared here, it's clear that many breast cancer patients are beating the odds.

About Citeline

Citeline, a Norstella company, powers a full suite of complementary business intelligence offerings to meet the evolving needs of health science professionals to accelerate the connection of treatments to patients and patients to treatments. These patient-focused solutions and services deliver and analyze data used to drive clinical,commercial, and regulatory-related decisions and create real-world opportunities for growth.

Our global teams of analysts, journalists, and consultants keep their fingers on the pulse of the pharmaceutical, biomedical, and medtech industries, covering it all with expert insights: key diseases, clinical trials, drug R&D and approvals, market forecasts, and more. For more information on one of the world's most trusted health science partners, visit Citeline.