

S P E C I A L I S S U E  
*Breast Cancer Consortium Quarterly*

DEMYSTIFYING BREAST CANCER



SPECIAL ISSUE EDITORS:

Grazia de Michele PhD

and

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October 2014

*Breast Cancer Consortium* (BCC) is an independent, international organization that promotes collaborative, multi-disciplinary initiatives aimed at increasing understanding of the social, cultural, and system-wide factors affecting breast cancer. We provide information to the public, media, and opinion leaders; develop analyses, exhibits, and multi-media tools; conduct research; share research, tools, and capabilities; and raise awareness of socio-cultural factors impacting disease. BCC members develop collaborations, leverage institutional resources, and seek grant-based funding to finance our projects.

*Breast Cancer Consortium Quarterly* (BCCQ) is the official publication of Breast Cancer Consortium, published four times per year, and featuring work from members and other contributors. Our writers range from social scientists to health advocates and journalists specializing in the social, cultural, and economic aspects of breast cancer. Content includes articles, research briefs, book reviews, film reviews, interviews, social media highlights, public policy updates, literature, photography, and artwork. We highlight academic research, critical advocacy, current news, and personal stories that speak to larger issues.

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# S P E C I A L I S S U E

## *Breast Cancer Consortium Quarterly*

This special issue of the *Breast Cancer Consortium Quarterly* edited by Grazia de Michele and Cinzia Greco highlights compelling stories typically missing from the broader breast cancer narrative, the stories that bust myths, resist stereotypes, and unveil how social dynamics impact the experience of breast cancer; still inspiring and courageous, but in ways that serve to change the breast cancer paradigm.

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# Demystifying Breast Cancer

## INTRODUCTION by Grazia de Michele and Cinzia Greco

In her powerful essay “Illness As Metaphor” Susan Sontag drew a comparison between what she considered to be two of the most *metaphorized* diseases in recent history: tuberculosis and cancer. The former, represented as an illness affecting sensitive and weak people in the eighteenth and nineteenth centuries in popular imagination gave the sufferer a romantic allure. If “the reality of such a dreadful disease [had been] transformed so preposterously,” the same – according to the author - could not be said of cancer, “a disease which nobody has managed to glamorize.”

Sontag was writing in 1978, whilst receiving treatment for breast cancer. Cancer, and particularly breast cancer, was taboo at the time, a shameful secret to be hidden. Only a few years earlier, in 1974, the “coming out” of Betty Ford and Happy Rockefeller who revealed publicly that they had had mastectomies to treat their breast cancer, had broken the silence. Yet this revelation by two prominent figures still did not change the attitudes of ordinary women. Breast cancer remained a strictly private issue.

Since the early 1990s, things started to change in the United States. On one hand, breast cancer was strongly politicized by feminist and environmentalist movements throughout the country. On the other, the disease was quickly swallowed up by market-based philanthropy in alliance between corporate capitalism and the nonprofit sector.

The [story of the pink ribbon](#) is particularly telling of the how concerns brought forward by the breast cancer movement were appropriated by organizations and companies, including pharmaceuticals, nonprofits, and the medical establishment at large. Breast cancer, cast strictly as an individual problem to be solved with early detection and aggressive treatments, was no longer stigmatized as it had been in the past. Instead, it had become an opportunity to celebrate the virtues of “survivors” and the self-empowerment potential of the disease.

The first breast cancer ribbon was not pink. It was peach. Charlotte Haley whose daughter, sister, and grandmother had been diagnosed with breast cancer gave out handmade peach ribbons along with a card that asked people to wear the ribbon to bring attention to the fact that only a tiny fraction of the National Cancer Institute’s annual budget went toward cancer prevention. Haley’s ribbon gained enough visibility that *Self Magazine* and the Estée Lauder companies asked for permission to use the peach ribbon in their second annual breast cancer awareness campaign. Haley refused. She did not want the peach ribbon to be commercialized and lose its political potency. Haley’s aim was to build a grassroots movement, not a brand logo. To avoid legal sanctions, Lauder and *Self* changed the color. The breast cancer awareness ribbon became pink, a color carefully chosen for its association with femininity.

Over the years the pink ribbon not only became a common symbol for breast cancer, it became a powerful and pervasive culture. No longer just a matter of selling products, women are sold reassuring but false

notions about what breast cancer actually is. Unproblematized and stripped of political implication, breast cancer is portrayed as a rite of passage, a transcendent and unquestionable journey, curable and winnable. In reality, this disease is not the same for everyone. Few want to admit that breast cancer kills -- not those cancers confined to the breast, the primary cancers, but those that become metastatic (spreading to distant organs, leading to life-long treatment, trading costs and benefits, until all treatments eventually fail). Such realities are muffled by louder, upbeat messages of survivorship.

The she-ro, the optimistic 'survivor' who fights her personal battle with breast cancer and wins, is the protagonist of the fairy tale that represents today's breast cancer story. Her exploits and victories are celebrated in books, movies, magazines, and at fundraising events. There is no room for characters with different stories to tell. Indeed, the typical she-ro is middle class and heterosexual, most often white and young, with her sexuality and femininity wholly intact. Stories of difference, of suffering or rebellion, of death, threaten breast cancer's caché and therefore the dominant narrative. As a result, they are silenced.

People with metastatic (Stage IV) breast cancer face ongoing physical challenges that make it even more difficult for them to make their voices heard. M.G., a 40-year-old Italian woman living with metastatic breast cancer writes:

*"For every lucky 'heroine' who, despite illness, surgeries and treatments, manages to do more of everything, there are thousands of women who have to go to hell and get back many times."*

M.G. wrote these words in an abstract she sent to us when we put out the call for submissions for this project. Although her abstract was selected for inclusion in the *Demystifying Breast Cancer* collection, she was unable to finish her story because of a decline in her health.

**This special issue of the *Breast Cancer Consortium Quarterly*** is a small but important attempt to challenge dominant discourses on breast cancer, giving the floor instead to dissonant experiences that rarely make their way to public outlets. The questions we wanted to answer through the stories of people who have had direct or indirect experiences with breast cancer were many.

For example, what does it mean to live with breast cancer and not want, or be able to, identify with the dominant image of the she-ro? And, how do social conditions, economies, geographies, backgrounds, and sexual orientations frame this experience?

Living with breast cancer, confronting death, and expressing oneself to spur authentic and open communication about this disease is a key focus of this special issue. The stories we present offer a *demystified* view, reflecting the lived experiences of women diagnosed with breast cancer in different parts of the world, from the United States to Belgium, Israel, Italy, Spain, and the United Kingdom, belonging to different social classes and ethnic backgrounds, and with different sexual orientations. Together, they offer an unprecedented look into some of the most overlooked aspects of breast cancer's multifaceted reality.

### *In this Collection...*

The story of U.S.-born Tutu Tedder told by her friends Stephanie Theobald and Ashley Savage, reveals how this queer performer spent the last three years of her life in the U.K. subverting traditional representations of her illness. Stephanie, a writer and journalist, gives an impressionistic and vivid portrait of Tutu through the memories of their friendship, until Tutu's death from metastatic breast cancer in 2012. Ashley, a photographer who partnered with Tutu in the pioneering photo-project "Cancer Sucks!," gives an account of his personal and professional journey with Tutu, and shares two photographs from the series.

If Tutu was surrounded by devoted friends, Natasha, a Russian Jewish immigrant to Israel, died in almost complete solitude. Only Nina Redl, a chaplain and nurse, was at her deathbed. Natasha, diagnosed with *inflammatory breast cancer*, was an inpatient in a small hospital and hospice in East Jerusalem when Nina met her. Natasha's husband and three sons could not care for her at home. Even as Natasha struggled with the cancer, her grief about the family she left behind in Russia seemed only to exacerbate her anguish that she would never see her children grow up. Natasha entrusted her suffering to Nina. In "Maybe in another life," Nina entrusts it to us.

"Overpass Girl" (O.G.) is a pseudonym created by Steve Davenport for a woman living with metastatic breast cancer in a collection of his poems published in 2012. Through a year-long email correspondence with O.G. and Davenport, BCC's executive director Gayle Sulik tells how the poet came to write about his life-long friend and why she preferred to remain anonymous. O.G. is, as Sulik writes, "the nameless, faceless person who could be anyone, or a lot of someones." In a time when survivor stories claim the spotlight, choosing not to reveal one's identity may just be a revolutionary act.

An artist and a writer respectively, Sarah Sutro and Judith Cohen met before breast cancer entered their lives. Sarah was 47 when she was diagnosed and Judith, 63. In "Resisting breast cancer culture" the two friends discuss their experiences and treatment choices over the years, concluding that their decisions were connected to age and societal views of women and women's bodies as well as their personal feelings about how to come to terms with a post-treatment body. Today, they spend more time discussing art than cancer, and they share some of their work in this special issue.

"The side effects of survivorship" written by Natasia Hamarat explores the social and personal impact of breast cancer treatment on younger women. She tells the story of Isabella, a Belgian woman she interviewed for her master's thesis. Isabella, now age 41, received one of the most commonly prescribed hormone therapies used to lower risk of breast cancer recurrence, the drug Tamoxifen. Isabella experienced severe side effects from Tamoxifen, but when she explained these to her doctors she earned the label of rebellious patient. Isabella's exasperation with the drug and her doctors inattentiveness motivated her not only to join a patients' association and mutual support group but to become an organizer.

Slightly older than Isabella, Che, a Spanish hairdresser, struggled with cancer treatment in addition to the financial difficulties that stem from being a primary breadwinner. Che's story written by BCC member

Ana Porroche Escudero, reflects one of the many hidden socioeconomic and contextual aspects of breast cancer. As a self-employed and manual worker, Che did not have access to the system of social welfare that the Spanish government offers to other categories of workers. Che did not hide her anger towards what she rightly considered an enormous iniquity. She told Ana that she did not dread the cancer itself, but the treatments and how they would affect her body, her mind, and her ability to work again.

When Theresa Palomares of Houston, Texas was diagnosed with metastatic (stage IV) breast cancer, she was asked to leave a support group. Having a cancer that spread to distant organs scared group members who had been treated for breast cancer and no longer saw evidence of the disease. Feeling sequestered, she joined an online forum for metastatic patients and thought about how to bring attention to the forgotten breast cancer. Never having sewn in her life, she started a quilt project. Theresa collected stories of stage IV women and men and stitched them into a quilt that is now touring the United States.

Many women, with or without breast cancer, resist constraining norms and structural injustices. Belinda Rita Silvestro, from the Southern Italian town of Brindisi, felt tremendously discouraged when her mother died of breast cancer after months of silent suffering. Together with other women, she created an environmentalist association called "The Red Stroller" to build a better future for the community. Using the symbol of a red stroller with a smokestack, the group continuously and fearlessly denounces local industries and politicians for polluting the local community and putting themselves and their children at risk.

The essays in this issue aim to reconnect breast cancer with the real world, showing that it is not just possible, but necessary to resist dominant discourses. Combining writing and visual art, these stories speak a different language, a language of reality and freedom, a language that is, itself, a subversive act.



Grazia de Michele    Cinzia Greco

## OVERPASS GIRL: "THE POWER OF ANONYMITY" by Gayle Sulik

Gayle Sulik PhD is a medical sociologist, founder and president of the Breast Cancer Consortium, and author of *Pink Ribbon Blues: How Breast Cancer Culture Undermines Women's Health*. She tells the story of Overpass Girl, O.G., as poet Steve Davenport calls her.

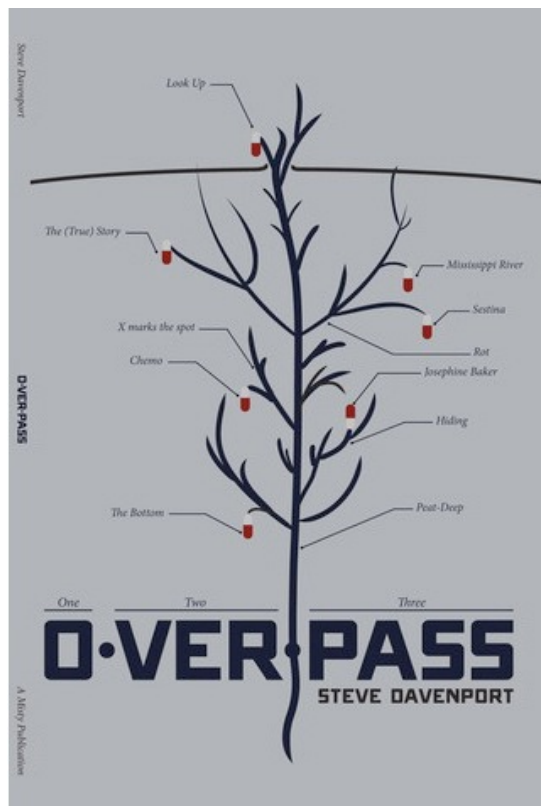
**Somewhere Overpass Girl bruises, blows, burns.**

**Somewhere retreats. Somewhere folds in. Somewhere**

**enthralled, ravished, betrothed.**

-- "Good Housekeeping," from *Overpass* by Steve Davenport

When Steve Davenport opened his email that day in 1999, he had no idea his best friend from senior year in high school, a woman he'd lost touch with for 17 years, would end up a character in one of his books. In *Overpass*, a collection of 47 poems published in 2012, Overpass Girl (or O.G.) hovers above the terrain of the Illinois floodplain. It's as good a place as any to tell a story of friendship, and cancer.



Who is O.G.? How does she feel about being an anonymous player in a poet's intimate and unapologetic rendering of her life with metastatic breast cancer? Somewhere Overpass Girl bruises, blows, burns. Somewhere retreats. Somewhere folds in. But somewhere is not just anywhere. Overpass Girl exists in real time and space. She lives and breathes. She reads about herself in the third person. Somewhere enthralled, ravished, betrothed.

Overpass Girl is the nameless, faceless person who could be anyone, or a lot of someones. That was the point. That was why she gave Steve Davenport permission to tell her story, from his perspective, while claiming no ownership for herself. In an era when stories of survivorship carry significant personal and social currency, anonymity is the exception to the rule.

When I read *Overpass* and Davenport's companion essay 'No Apology For Happiness,' I felt O.G.'s ominous presence. I recalled the people I loved, with cancer, and that

unbecoming grief that persistently burrows into one's heart after deep loss. Raw and unembellished, Davenport's words rang true.

*“As in I drive in rectangles above a lake of gasoline carrying news about a friend’s cancer. Overpass Girl’s cancer. As in I drive and drive and I have this friend from childhood who has this cancer and I am making myself angry, layering it on top of my hard-wired happiness. I, I, I, I as in the straight lines of road and railroad track and refinery fence and levee, all of it forcing a script of right angles I trace and retrace with the wheels of this beater van because I have no choice, the engine clicking like synapses firing tiny holes in my brain pan.”*

I had an Overpass Girl of my own, a few of them. I wanted to know more about Steve’s.

### ***How I Met O.G.***

Steve Davenport and I had already been corresponding. I loved his work and featured several of his pieces on the Breast Cancer Consortium website. I inquired about O.G. “How is she doing?” Steve copied O.G. on his emailed reply, “Now’s as good a time as any to introduce you. O.G., meet Gayle. Gayle, O.G.”

I told O.G. I’d like to set up an interview with her about *Overpass*, why Steve wrote it, and her experience reading herself in it. This started an email conversation that lasted more than a year. I learned about O.G.’s history, her attitudes about breast cancer and pink ribbon culture, and her everyday life as a woman with metastatic disease.

For instance, I found out that O.G. came from the so-called “wrong side of the tracks” and that when they were in high school she had to cross an overpass (literally) to visit Steve. Her family life was volatile, so she welcomed spending time with his family, people who were accepting, with no airs, no judgment. She and Steve were just friends who would hang out, nice and easy.

After graduation O.G. married a man in the military and moved out of the country. Steve went to college. Without electronic communications and social media, it was harder to keep in touch in those days. But circa 2000, a flurry of emails followed by Facebook messages and a 35th class reunion rekindled that old, close friendship. Then things got blurry.

After a few years of benign breast biopsies, O.G. was diagnosed with advanced breast cancer. During this time, she and Steve communicated more often. She sent him long, rambling emails and apologized for them, but kept writing. O.G. told him the truth about her relationship with cancer, something she couldn’t seem to do anywhere else. She was holding down a job, was a caregiver to an ill parent, felt like she had to put on a brave face for her kids, had a husband who didn’t want to talk about it. The marriage didn’t last long after the diagnosis.

From the biopsy on, Steve rode out the good and not so good news, asked questions, listened for details.

*“It’s gone. It’s back. Radiation burns. Clinical trials. Insurance. Needle biopsy.”*

O.G. felt like a hamster in a wheel, spinning to keep her life from falling apart. She was sick, terminal, doing the best she could, angry she couldn’t share her deepest feelings with most. Public spaces like



Facebook were especially painful. Everyone had an opinion, and O.G.'s didn't seem to matter — unless it needed to be “corrected.” Steve took it all in.

At some point, Steve felt the need to put ink to paper (or fingers to keyboard). He'd send O.G. snippets of poems, a few lines at a time. If he wanted to check something for accuracy, like the needle used to take out bone marrow, he'd ask. But where his writing was concerned, O.G. made few, if any, comments.

O.G. wasn't sure why Steve started writing about her, but thought it might have been cathartic. “I think he felt as we all do,” she said, “helpless, and this was something he could do.” Then O.G. added,

*“He supported me, cheered me on in his own way...Perhaps he was...making sure that he said things in a way that I couldn't. I was always searching for real stories about real people with real feelings and I was having a terrible time finding them. It was quite therapeutic for me to be able to just lay it all out there.”*

O.G. told me more about her quest for real stories, rather than those “cute little sayings” that seem to be mantras for the newly diagnosed. I laughed when she wrote:

*“What drug are you on that makes you not have a care in the world except what to pack in your pink backpack for your first day of chemo, which, by the way, will be attended by four of your closest friends who will don boas and tiaras and decorate you with similar, but much more flamboyant garb? I [keep] waiting for the male strippers to arrive to entertain during infusion.”*

*“It's like trying to slay a dragon with a lollypop.”*

O.G. doesn't mince words. But she keeps them to herself most of the time. “That rock and hard place is so uncomfortable,” she says. “I don't like muzzling myself, but I do it. Truth is so unacceptable these days. It's always perceived as negative.” If truth is synonymous with negativity in the cancer world and positivity is the cornerstone of survivorship, then there is no place for truth in that world. To speak her truth, O.G. needed to give her words and her identity away, to a trusted poet and friend.

*“A few days ago Overpass Girl, minus one breast already, was sedated for a biopsy. The night before the procedure, she sent me an email with a subject line borrowed from her favorite novel, Holy Book of the Beard. “Spit in the face of cancer” is Helga's advice to her daughter, advice that her daughter shares at her mother's wake. In that email Overpass Girl told me there's a letter in a trunk. For me. Heat-seeking with my name on it.*

*Tonight the word is Trunk.*

*Is Letter. Is Truth-Telling.*

*Is No-Escaping.*

*A letter for me, to be opened one day, right in there with letters to her grown children, her husband. A letter to be sent if and when. Another bomb.”*

Overpass Girl lives with metastatic breast cancer. She argues with her insurance company to get approvals for tests and treatments. She fears that the metastasis on her femur may no longer be “playing nice” and that chemotherapy drugs for life may be the only option. She steers clear of pink fanfare, and offers an ear when others come to realize that the well-intentioned advice to keep up one’s chin in the face of cancer may have the unintended effects of squelching emotions and silencing truths. She sends long emails, and Steve Davenport turns them into poems.

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**NATASHA: “MAYBE IN ANOTHER LIFE” by Nina Redl**

*Nina Redl is a health care chaplain who has worked for many years with oncology patients. She tells the story of Natasha, a young woman with Inflammatory Breast Cancer she met when she was working in the Middle East.*

I met Natasha towards the end of her life. A Russian Jewish immigrant to Israel, she had taken a very unusual road. Instead of settling in a Russian Jewish neighborhood in Tel Aviv or Jerusalem, she moved to Eilat and lived in a part-Bedouin, part-Arab neighborhood. Working in one of the big hotels she felt connected to her Arab coworkers. They “adopted” her as “another daughter.” Natasha learned their language, culture and customs, and within a short time converted to Islam. Within a two-year time span she married Ali, one of the cooks at her workplace, and they started a family. Natasha had three sons before she and Ali moved to East Jerusalem to be closer to his family.

During their first winter in Jerusalem Natasha fell ill a lot, surprisingly so for a strong young woman who grew up in Russia and was “used to cold temperatures.” But when summer came, she increasingly felt weaker. Neither she nor Ali could afford a doctor. As a poor Arab family, they had no easy access to the Israeli (primarily Jewish) government subsidized health system. In the small, local clinics that saw her for free, she was diagnosed with chronic exhaustion, was told to rest and avoid another pregnancy. The Bedouin healers they saw thought she may have suffered from an illness of the heart. Given that Natasha had given up her Judaism for Ali and her family, her illness, they said, may stem from unresolved grief that Natasha and her ancestors were feeling in their souls.

Despite her new life, Natasha did miss her birth family, religion and country of origin. Hoping that having another child would heal some of her grief, pain and fatigue, she became pregnant again and gave birth to a daughter. Natasha got scared when she was unable to breast feed due to pain, lack of breast milk, and exhaustion that barely allowed her any normal activity.

Using up her last savings, Natasha paid for a doctor's visit in one of the larger Arab hospitals where she was diagnosed with Inflammatory Breast Cancer (i.e., a rare type of breast cancer that develops rapidly, making the affected breast red, swollen, and tender). Already "locally advanced," meaning the cancer has spread from point of origin to nearby tissue and possibly lymph nodes, Natasha's cancer had also spread to her lungs. The hospital gave Natasha treatment pro bono since she was so young, and had no funds.

After several rounds of chemotherapy and radiation, it became clear that Natasha's illness was terminal. A last, desperate attempt at radiation treatment left her with severe burns that turned her entire chest into a partially scarred, infected and tumorous wound. Any contact caused pain. The wound grew and festered along with her cancer.

When Natasha and I met, she was an inpatient in a small hospital and hospice in East Jerusalem that took her in due to her family's inability to care for her sufficiently at home. I served as a volunteer chaplain and nurse in that hospital. Shy at first, Natasha refused to let anyone see her wound or touch her. Afraid that the smell of the wound would drive someone away, she lay in bed facing the wall, hugging the bed linens tightly around herself, pretending to sleep, so as not to encourage anyone to come close.

The wounds on Natasha's chest were so severe and prone to infection that she was bedridden, unable to dress or do much else without intensive pain medication. Many people, including her family, stopped visiting. The image of Natasha "dying from the inside out" was too terrible to witness. Natasha never encouraged them to come either. Her fear of being a burden and a failure ran deep. But for her, it was not the wound or the cancer that ate her up; it was the loneliness, sadness and grief. Natasha told me at one point that the wound was nothing but a physical representation of how she felt, having lost her family not once, but twice. The illness meant loss of family, much worse than any physical ailment.

During her first few days in the hospital, I just sat next to Natasha's bed. I brought her food and helped her to the bathroom. Despite dying of cancer, she was a beautiful and lively young woman. I wanted her to know that even though her cancer was visible, she was so much more than her cancer. Hence in this beginning stage, my only goal was to help soothe the emotional pain she suffered.

When we talked we spoke about many things unrelated to Natasha's illness, as little by little she started opening up to me. In the long hours we spent together she told me about her dreams, her hopes for a better life "the next time around," feeling that she would die the moment she lost her hair, her struggle to come to terms with the fact that not only would she never see her children grow up, she would barely get to see them before she died.

Natasha said she wanted to be remembered as a strong, beautiful woman and mother who loved her children and her husband. She hoped that leaving her country to start a new life on her own would not be viewed as selfishness, but as strong, courageous determination to create a better future for herself. She grappled with, in her view, how God, society and her family abandoned her during her illness and how in dark moments of despair she felt like she might have deserved it for leaving her roots behind.

Over the next few months, seeing and feeling her body die was a daily struggle for Natasha. She longed for beauty, health, and the dream she came to this country for; freedom and a family, both of which were being cut short. Our staff tried to help her find peace with herself. With a lot of time, patience, acceptance, and caring we became a family, even though we would never be more than a substitute.

It was Natasha's wish that no matter what had happened in her life she would not be forgotten, and that even though she suffered loneliness and tragedy her story of strength, beauty, and determination despite cancer would be told. Natasha died with only a few staff members around her and a dream that never subsided—in her next life, she would be beautiful and a mother again. I pray she will.

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**CHE: "MANAGING CANCER AND SELF-EMPLOYMENT" by Ana Porroche Escudero**

*Ana Porroche Escudero PhD is an anthropologist and member of the Breast Cancer Consortium living in the U.K. She tells the story of Che, a Spanish hairdresser whose working life has been turned upside down by breast cancer.*

Che represents one of the many hidden socioeconomic and other contextual aspects of breast cancer, one where certain women are not able to afford sick leave because they are their family's main breadwinners, and because it seems as though the sword of Damocles hangs over their employment. Far more disturbing, as in the case of Che, is that the disabling sequels of cancer treatments present a grimmer fate for those who are self-employed and work in manual occupations.

I met Che when she was in her mid-forties and had owned a hair salon for over 15 years in a Spanish provincial city. She was married to a man who had been unemployed for a long time and who did not provide her with much emotional support. They had a six-year-old son together.

To help me understand Che's experiences with cancer, she explained her complex employment and family history. Passionate about her career, she told me that she quit her job after ten years working for someone else's hair salon to open her own with the help of a loan and a willingness to work copious hours. As is the practice for hairdressers in Spain, Che worked a minimum of 9 hours daily, not including the extra time spent on administrative matters, including tracking payments, paying taxes, contacting suppliers, and managing relations with employees and customers. Because of the hardships of starting a salon from scratch Che and her husband delayed having children. Only when her business was well established and she was able to hire two additional employees to help out did the couple decide to have a baby. It was at this point, when Che was 39 years old, that things started to go wrong.

Che loves her job and talking to her clients. For her, hairdressing is an art that gives her emotional relief and financial independence. In fact, most of Che's clients expressed a preference for her over her employees. So when Che was pregnant she did not think maternity leave would be a good option. Without her there to serve her clients, it could negatively impact her business.

To support his wife's work, Che's husband opted to take paternity leave. He was fired for no apparent reason before the leave began. Che believes that although it was his right to do so, her husband was dismissed unfairly simply because he took the leave. Following his dismissal, Che's husband suffered from depression, making it more difficult for him to secure any sort of employment. Things got worse after Che was diagnosed with breast cancer.

Che knew for over 12 years that she had a small lump in her breast but was assured during regular checkups that she had no serious condition. Two years prior to our interview, Che noticed that this lump was bigger, "more static" and uncomfortable. The ultrasound and cytology tests found no abnormality, so her gynecologist suggested that she schedule regular appointments every six months. Increasingly concerned about her diagnosis and a now painful lump, Che booked an appointment for a breast screening after receiving an invitation from the Spanish Association against Cancer – endorsed by the Spanish Ministry of Health. At the appointment, two lumps were detected: a small mobile lump she'd had for two years which was not cancerous, and the ever growing one that was.

The negative impacts of being diagnosed with cancer, having treatment, and getting sick were many, and immediately tangible for Che. First, she knew all too well that with every day she missed work, she would lose clients; her less experienced employees did not perform at the same level. When I asked Che about her regulars, she answered straight away, "Today, not even your husband is loyal." Second, without clients, there would be no income to pay for food, bills, taxes, or employees' salaries.

When I met Che, she'd had one chemotherapy cycle only. She could not receive the second round because her immune defenses were too low. Che told me that she did not dread the cancer itself, but the treatments and how they would affect her body, her mind, and her ability to work again. She said to me:

*"I am so afraid of the treatment because I don't know how much it will deteriorate my immune system. But I don't have any option. I can't forget about my business even though I want to. No matter how many times the psychologist tells me to forget about it, it is still my problem. If they told me that I would be going to earn monthly the same amount I used to earn as a hairdresser I would be relieved from many problems."*

At the time of our interviews, self-employed workers in Spain did not have the right to claim unemployment benefits. Until recently, they did not have rights to sickness benefits from the state either, which is nonetheless, very modest and worsening with draconian fiscal cutbacks imposed by a conservative government. As Che says:

*“They don’t give a damn if you have to close your business. Because if you are the owner and you are sick, it is your problem... It makes everything difficult and doesn’t allow you to be ill.”*

Given the insufficient safety net that Spain’s social care system provides for its self-employed people, many pay for additional private health insurance. Too often such insurance companies deny compensation claims, arguing that diseases such as cancer were not covered by the contract. Che recalled such an interaction with her private insurance company some weeks before our interview:

*“As I am self-employed, I want to receive my sick benefits from the first day I am ill. Thus I have a private insurance. I found out that they will pay me at the end of the treatment because it is going to be a long sick leave. I asked them ‘Don’t I have to eat every day? Do you think the money comes from heaven?’ I wrote them a letter asking if I could have an advance. I see myself... I see myself thrown away like a cigarette butt (colilla).”*

After this exchange, Che’s world fell apart. She worked extremely hard to keep her business afloat. She managed to meet the Inland Revenue’s harsh requirements and private insurance payments. She sacrificed her dreams of having a large family, even her relationship. Having gone through all of this, Che thought she deserved “the right to be ill.” Movingly, she said:

*“If they said, ‘Dear patient, we are going to give what you have earned. Because you deserve it, because you have been paying taxes all of these years. So we believe you deserve it for a year.’ Because I do believe I deserve it. I’ve been working for 15 years self-employed and I always paid my taxes. I never withheld anything. Even during regular inspections they could never find anything wrong because everything was legal.”*

Che’s relationship with her husband grew worse. The tension and strain of living with a man who was mentally ill, and who did not support her economically or emotionally, was combined with the constant worry of not being able to afford time to be sick and recover from her illness:

*“He complains that I have many visitors at home, [and this] is disrupting his life, of course. He also accuses me of not doing anything at home. But this time I really need someone to take care of me. I decided I had to move to my parents’ and that he would take care of our son. I have much bigger problems than the illness itself, so at least in what concerns the house I can be relaxed. I can guarantee you that I won’t have been able to come to this interview otherwise.”*

In addition to constant worries, Che felt the burden of being the only breadwinner and guilt about “leaving” her son with her husband and in-laws. Her concerns reflect the complicated web of gendered values that make living with cancer even more difficult. These, in turn, can worsen a patient’s mental and physical health, as is apparent when Che justifies her decisions.



*“If I die my son will lose his mother... [This situation] corrodes me tremendously, bitterly and viscerally... How can a balance exist if the strong person in the couple gets sick now?”*

Che started with very little, but she managed to excel in her career even when it interfered with her aspirations to have a larger family. She bought a house and paid off the loan for her business. She prepared “for the future.” She saved money and paid for additional private health insurance. But although Che might be able to recover from cancer, the scenario for her future is a frightening one. At age 45, she is a sole breadwinner, with a child, a husband who is mentally ill, and a meagre allowance for sick leave, possibly none at all. Her occupation is not one that tolerates the implications and side effects resulting from armpit surgery, making it unlikely that she will be able to work in the only job for which she is qualified, a situation exacerbated by the difficulty of finding work given her age and disability.

For people like Che, fortunes can easily take a downward turn with a cancer diagnosis. Her case illustrates well how dealing with cancer involves much more than eliminating cancer cells from the body. The social circumstances in which women live can be as scary as the treatments they endure.

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### **ISABELLA: “THE SIDE EFFECTS OF SURVIVORSHIP” by Natasia Hamarat**

*Natasia Hamarat is a Belgian PhD candidate in sociology of health at the Université Libre de Bruxelles. She tells the story of Isabella, a young woman diagnosed with breast cancer whom she interviewed during her earlier graduate work. Isabella’s story shows how hard it can be to live with the side effects of hormone therapy, especially when these are downplayed by physicians.*

Before I introduce Isabella let me tell you about a drug called Tamoxifen. Both pre- and post-menopausal women may be prescribed this drug as a treatment for some types of breast cancer. The drug inhibits (blocks) the estrogen receptors in breast tissue to reduce estrogen’s ability to fuel cancer growth. The main goal of this drug, routinely taken for five years, is to help prevent recurrence should there be any breast cancer cells lingering in the body after treatment. Oncologists generally maintain that Tamoxifen is “well-tolerated,” a vague, euphemistic concept that generally ignores or underestimates side effects. Many patients, particularly pre-menopausal women, vehemently disagree with this statement. An estrogen-reducing drug like Tamoxifen may induce early menopause or cause articular (joint) pain, sleep disorders, weight gain, loss of libido, hot flashes, and a range of other side effects that may seriously impact health and disrupt quality of life.

Isabella, 41, lives in Brussels and was diagnosed with breast cancer four years ago. Her mother died from ovarian cancer before age 50, and she understands that a family history involving both of these cancers

increases her risk. Yet she does not dwell on the traumatic moments of her life. She said at the beginning of our interview that “to de-dramatize, it’s my forte!” Isabella presents herself as a “lover of life.” When she told me her story, she had a funny anecdote for every episode of her illness, mocking her doctors and close relatives alike. This aspect of Isabella’s personality contributed to her belief that she *should not* have to be less healthy or vital because of cancer. If medicalization was going to lead to a potentially devitalizing situation for Isabella, she was ready to criticize it radically. Such was her experience with Tamoxifen.

After Isabella started taking tamoxifen, she felt like a different person. The hot flashes were not just frustrating, they were physically draining. Isabella explains,

*“One can think that hot flashes are just feeling hot, that [they’re] annoying. But hot flashes are not just feeling hot... I become like a pressure cooker, and I consume a lot of energy... so it means that when [the flash] goes away... my energy falls... It is exhausting!”*

She goes on to say that the depletion of estrogen has had negative effects on her emotional well-being:

*“I mean, they took a hormone... [a] pleasure hormone, [found in]... laughter [or] in the simple pleasure of eating or in an orgasm. I said to myself ‘I feel I need this. This is what makes us feel more alive.’ I do not enjoy things at a hundred percent, and I miss it.”*

Isabella was exhausted, but she also couldn’t sleep. Sleep deprivation thwarts your zest for life, dumbs you down, leads to mistakes, affects self confidence, and can have lasting effects on one’s social and professional life. Isabella’s insomnia led to distraction at work, hypersensitivity, and poor morale that affected her feelings of self-assurance and her ability to do her job. She describes,

*“I couldn’t get asleep. I didn’t get to take naps during the day, so I fell asleep at three, four, five, six in the morning, depending on the day. In my job [she’s an accountant], I can make little errors... luckily I didn’t make any serious ones, but I have the impression I’m making more errors. Sometimes I [feel like I’m] becoming stupid. It’s as if all my skills dropped because of the fatigue.”*

Because Isabella was more sensitive and cried more easily after taking Tamoxifen, it was hard for her to keep up her spirits. She wasn’t depressed in the classical sense, but she was no longer the first person to laugh or joke around like she used to do.

Unfortunately, Isabella got no relief from these side effects. Her doctors didn’t seem to bother with them and instead labeled her a rebellious complainer, something that deeply angered her. In her words,

*“They [the doctors] don’t give a damn if I’m not sleeping... They don’t look for a solution. They write in my medical dossier: complains of insomnia, but it ends there. When I see my dossier, I see mainly that everything has been well-explained to me and that I’m rebelling against this, against that. But I don’t agree with the fact that everything has been well-explained, and I don’t agree that I’m rebelling.” (She laughs).*

Isabella's exasperation about her treatment and her doctors' inattentiveness to side effects and aftercare, motivated her to join a patients' association and a mutual support group where patients may share their common and individual experiences. In fact, today she's an organizer for one of these groups to bring attention to the social and personal impact of cancer treatment on younger women. Despite institutional measures in Belgium and elsewhere to personalize cancer treatment, the medical profession continues to ignore entire parts of the disease experience, particularly the social aspects.

Hormone therapy is a striking example of a type of silence in biomedicine about the impact of side effects that negatively affect dignity and quality of life for young women with cancer. Isabella tells her doctors that even though hormone-regulating drugs may have the potential to add some time to her life, she knows they will not protect her from relapse. So she wonders, "In the end, what am I protected from?"

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### **TUTU TEDDER: "PUNK CANCER NOT PINK CANCER" by Stephanie Theobald**

*Stephanie Theobald is a British journalist for publications including The Guardian, The Sunday Times, and The London Evening Standard. She has also published four novels. Her third, **Trix**, about a road trip across America, was inspired by her close friend Tutu Tedder. Tutu Tedder, a performer who died of breast cancer in March 2012, is the subject of this article.*

**"Even if you've lived your life like a complete slob, you can still die with terrific style."**

*-- Design for Dying by Timothy Leary (1997)*

Life's not a rehearsal, the cliché goes, but actually it is. We spend our whole lives preparing for our last scene, our span's last inch, when, as John Donne said it: "gluttonous death will instantly unjoint" our bodies from our souls. Whether you believe that life after death is some glorious stage dive into the cosmic beyond, a plug pulled abruptly from a socket, or an encounter with a bearded man in a long white robe, thinking about dying is vital. (And those who say death is a "morbid" subject are condemning themselves to a bad school play ending, as opposed to the Larry Oliver production we all hope for).

Timothy Leary kept up this Broadway extravaganza image of death in his last book, *Design for Dying*, when the LSD apologist said that dying was the most important thing you'd ever do because, "It's the final scene of the glorious epic of your life. It's the third act and, you know, everything builds up to the third act." How we do the dying thing may be just as, or more important, than anything else. So here I am writing about dying.



It used to be sex that inspired me to write. Sometimes it was love. And then the person who taught me to love as well as a thing or two about sex, started to die from breast cancer. In the course of life, Tutu (born Kristen Tedder in California in 1966), was a nanny, a dominatrix, a club runner, an epic pot smoker and specifically, a deranged and incredible showgirl who died in March 2012, aged 45. Her

Courtney Love/Doris Day Schizophrenic strip tease show became legendary at Kabaret in Golden Square with the likes of the Gallagher Brothers and Damien Hirst because she was a stickler for a good show. I remember going with her to see *Moulin Rouge*. She hated Nicole Kidman. ("What kind of courtesan is that?" she groaned. "Looks like she hasn't been fucked in years"). At the same time, she understood the problems of being female. "It's hard to pull off being a woman," she used to say. "That's where the drag queens come in."

Tutu was a dazzling presence. In 2002, I wrote a novel inspired by her called *Trix* – a kind of *Thelma and Louise* meets *Fear And Loathing in Las Vegas*. But when I happened to be present at her bedside last March when she died, I was poleaxed with horror and fascination as I watched the last vestiges of life ooze and shudder their way out of her. Even the Palliative Care guy from St Thomas' hospital conceded it had been a 'dramatic death.' When she was gone, I thanked her for giving me a front row seat at the most amazing show I had ever seen. I think I then laughed hysterically, then cried, then observed the other four people who'd witnessed the dying scene, reeling around the flat. If some junkie had peeked in that morning, looking for a little something for the weekend, he would have licked his lips and assumed that there was an exotic variety of drugs circulating from fantastic E to paranoid skunk to weird ketamine.

I decided to write a play about the whole unfathomable experience. I'm calling it *Pre-Disco Tension* in reference to that time before a party when you are getting ready for the night and 'spazzing out' with nerves, as Tutu would say. In the same way preparing for death can be a mind bogglingly terrifying time or horribly exciting time, depending on which way you look at it.

*Pre-Disco Tension* is about a group of queer friends who take recreational drugs. They're used to finding themselves tripping in outer space, half in love with easeful death, claiming afterwards that if they'd died at that very moment, flying up there in the sky with diamonds, they'd have been fine with it, etc, etc. And then one of them, a charismatic showgirl, finds out she is going to have to do death for real. And if you're going to perform your own death, as we all must, then what is your performance going to be like?

I'm not saying that Tutu's dying performance was easy. There was a lot of stage fright involved. Not for her the famous *Five Stages of Grief* of Elizabeth Kubler-Ross (denial, anger, bargaining, depression, and acceptance). The night before Tutu died she screamed, "I don't want to fucking die!"

But she did her best. Some of her last days were grim, but some of them were surrounded in a mysterious type of glamour, as if this was all part of some demented David LaChapelle shoot. One time I visited and witnessed the tableau vivant of Tutu sleeping in her bed, surrounded by a group of Weeping Women as Superman flew overhead through the clouds on the TV. In her final days, there were so many odd-looking friends crowding into her house to give her a final send off that some of the locals on her Elephant and Castle housing estate believed a crack house had set up.

Tutu didn't go quietly. The last year of her life was spent sitting for a series of photographs taken by her friend Ashley Savage, who'd documented her various showgirl personas throughout her London life. The ensuing show, called 'Punk Cancer,' aimed to smash the whole "pinkification" of breast cancer. Photos range from a beaming Tutu posing Bettie Page-style on a radiation table, to an anarchic hair-shaving session pre-chemo and a pot-puffing love-in with her childhood teddy bear ("Teddy") who was always by her side during the last months.

"It's not a perfect world," she said towards the end, "but you just have to get up, sing your song, keep your helmet on and things will get better. Things will always change, remember that. Things will be good, things will be bad."

The thing about death, though, is that you never know how you're going to react when the time comes. If you want more of a sense of *Pre-Disco Tension*, listen to 'Tomorrow Never Knows' from the Beatles' 1966 album, *Revolver*. The song was written by John Lennon in response to his reading of Timothy Leary's *The Psychedelic Experience: A Manual Based on the Tibetan Book of the Dead*. The book advises that the feelings you experience when you take LSD are similar to the dying process, and need similar guidance. But mainly I love this song for its thrashy, trippy, incredibly modern sound which is perfect for the short, mad cabaret numbers that intersperse *Pre-Disco Tension* (because unlike death, theatre can be so boring). Right.

*Photo Credit: The picture of Tutu Tedder was taken by Stephanie Theobald circa 2000.*



## CANCER SUCKS: “THE LEGACY OF TUTU TEDDER” by Ashley Savage

*Ashley Savage is a photographer whose work has been published and exhibited both in the UK and abroad. He collaborated with Tutu Tedder on the documentary photographic project they entitled, ‘Cancer Sucks.’ In line with Tutu’s last wishes, he is looking for funding, publications and galleries willing to show this work.*

Since meeting the showgirl, Tutu, in 1994 when she was performing at the legendary Madame Jojo’s in London’s Soho, we collaborated on many occasions. She was my friend, my favorite muse. When she was diagnosed with breast cancer in 2009, it seemed obvious that we would document the experience.

Prior to completing my BA (Hons) degree in photography in 2003, I had trained in counseling and psychotherapy. As such, I had been interested for some time in harnessing the therapeutic potential of photography. Tutu shared this interest, keen to use her body as a medium of expression. In many of our photo shoots we sought to explore not only the cancer but her enduring encounters with depression and self harm, as well as my own. Since undergoing the onslaught of surgery, Tutu had many regrets about the damage she had intentionally inflicted upon her body during periods of self harm. Those scars are visible in many of our photos and in terms of her life experience, are almost as relevant as the scars from her mastectomy and other surgeries resulting from treating the cancer itself. As a long term depressive, I too benefited from engaging in this project as it gave me focus and a reason to be alive and look to the future, even when I became aware that Tutu would not survive.



With the *Cancer Sucks* project, Tutu wanted to take back a degree of the control and autonomy that the prescriptive nature of treatment plans and frequent hospitalization threatened to strip away. As the project evolved, we realized how important it would be to document the progression of the disease as realistically as possible, to show what it was like to live with cancer from Tutu’s perspective — the traumas of surgery, the complexity and range of emotions, the highs and the lows.

Eager to break from the generic breast cancer tableau, those pink and fluffy images that fail to reflect the realities of the disease, we knew we would alienate mainstream outlets. Tutu endeavored to be true to herself. Appearing in photographs that were at times graphic, she refused to compromise on revealing truth. Even on her worst days, she wanted me to keep photograph-



ing, however bad she felt. From the beginning we agreed to keep the camera clicking all the way to the end, whatever that end would be. These photographs would be our legacy and, for Tutu, they were the most positive thing to come out of her tragic diagnosis.

Our photo shoots were not always convenient or easy to arrange. Once when I was photographing Tutu having chemotherapy treatment, we were asked to stay at the far end of the room so as not to disturb other patients. Subsequently however, several older women also with tubes in their arms got up and walked toward us, wheeling their chemotherapy stands along with them. They were fascinated that anyone would want to record the traumatic experience of having cytotoxic chemicals dripped into their veins in an attempt to stop cancer in its tracks. When we explained our project, they understood. They wanted to watch and ask more questions. It was fascinating how the photographic process opened up a dialogue and transformed the atmosphere in the treatment room momentarily to one of curiosity and wonder.

On another occasion we were in the hospital waiting room before one of Tutu's radiotherapy treatments when she opened her bag, took out a viking helmet and placed it on her head. As soon as the other patients saw her, the sombre atmosphere in the room lightened up. Everyone became more animated and started asking questions. Tutu kept the viking helmet on for as long as she could that day; she seemed empowered by it. Most of the technicians were as fascinated as the patients. They showed enthusiasm for our vision and, despite the red tape, helped us to obtain regular approval to photograph in the hospitals.



Since the same people frequented both hospitals, they often asked how the project was going, what we would do with all those photos. Our ideas always seemed to get people talking about their problems, their loves, their fears, their hopes for the future, which was exactly what we had wished for. Some of the

patients we met while I was attending the hospitals with Tutu died. I hope our interactions had a positive impact on them in some small way. I know they did for Tutu. And for me.

Though, sadly, Tutu died in 2012, I am hopeful that we can continue to show the work to inspire others to document the traumatic events in their lives. In reality, not everyone would be willing to do so in such a graphic fashion as our *Cancer Sucks* project. But there are many different modes, concepts and mediums to be explored and used. Tutu was a one off, an innovator, a real star who touched the lives of so many others during her relatively short lifespan. I miss her vivacity, humor and the unconditional love she shared with me. I hope her memory will live on through our pictorial collaboration, *Cancer Sucks*.

To view the complete photo series, visit the website, [www.savageskin.co.uk](http://www.savageskin.co.uk).

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#### **STAGE IV AWARENESS: "THERE IS A WAY" by Theresa Palomares**

*Theresa Palomares from Houston, Texas is a woman living with metastatic breast cancer. She is one of the initiators of the Inspired Metastatic Breast Cancer Advocacy Quilt and METS Collage project, whose aim is to raise awareness of the lack of research funding for stage IV breast cancer.*

In August 2011, I went for an annual mammogram to confirm what my general physician had been telling me for years, that the lump in my right breast was a "fibroid." More than half of women experience fibrocystic breast changes at some point in their lives, so it was a reasonable assumption. However, my life was forever altered when the results came back positive for breast cancer instead. I hurried to a breast surgeon to get the monster out. No easy feat, my surgical scars were so severe they left me with a crippled arm and damaged nerve endings. Following the chemotherapy and radiation treatments, I had neuropathy (weakness, numbness and pain resulting from nerve damage) throughout my body, damage to my heart and vascular system, and a weakened immune system.

My particular type of breast cancer grew both in response to the hormones estrogen (ER Positive) and progesterone (PR Positive). This meant that my ovaries, because they produce estrogen, were actually fueling the cancer cells. One of the drugs I took to block the estrogen attacked my uterus. My only option was to have a total hysterectomy, removing my ovaries and uterus. After being forced to make such life altering decisions, I realized that I had no real control over my disease. By September 2012, I developed a new back pain that was, I soon found out, caused by a metastasis (spread) of breast cancer to my spine. Still too small to treat, my oncologist told me it would be best for us to keep an eye on it, something I call the "wait and see game." The idea is that these drugs may deter the cancer from growing. When they fail in their job, the only other choice I'll have will be to be on chemotherapy for the rest of my life.

Life with these drugs can be extremely distressing. I recently had to switch from one drug to another because the one I had been on since my metastatic diagnosis was no longer working. In addition, besides bone metastasis in my spine and a small tumor in my liver, doctors found two nodule growths on my thyroid. I also have persistent headache: for someone with metastatic breast cancer, this symptom requires a brain MRI and PET scan to find out if the cancer has spread to the brain.

The biggest issue for me right now is that I have had to leave my home in Houston, TX to relocate to Oklahoma City. There is a 24-month waiting period for medicare due to disability rulings, so I have been without insurance since I was classified as disabled due to metastasis. I could not afford insurance; my home state made drastic cuts to the medicaid system; and criteria for enrolling in the federal breast cancer treatment program are income-based and designed primarily for one-stop treatment rather than the continuous treatment needed for a metastatic patient. As a result, I have had to rely on the Indian Health Services, which is responsible for providing medical and public health services to members of federally recognized Tribes and Alaska Natives. I am from the Delaware tribe, so to use the program I need to take up residency in Oklahoma.

When I was diagnosed with metastatic breast cancer, I realized the “survivor” label no longer applied to me. I could no longer be one of those pink-ribboned warriors who shout, “I’m cured,” and enforce “early detection” messages to raise money for “the cause.” With metastatic (stage IV) breast cancer, a “metster,” I was no longer in the PINK club.



When I first joined a local breast cancer support group, because I sought support from my community, I had no idea I first would be ignored and ultimately asked to leave because my situation scared the other “survivors.” I kept looking for a group that would understand, but the only support group for Stage IV breast cancer was 22 miles away. It was just on the other side of town, because I don’t drive due to my debilitating state, it might as well have been on the other side of the planet.

Resigned to operate from my home base, I joined an online forum for advanced breast cancer (ABC Forum)

called "Inspire." We kept seeing our metastisters dying, so some of us formed a Facebook group (Inspired Metastatic Breast Cancer Advocacy Group) to come up with ideas about how to bring attention to



metastatic breast cancer (MBC). Funding for MBC is a pittance (just 3-5 percent) of the total monies spent on breast cancer research. Most of the money goes towards awareness and “early” detection.

We started some petitions: one to ask “Breast Cancer Awareness Month” to be renamed “Breast Cancer and Metastatic Breast Cancer Awareness Month;” another, which is still ongoing and has collected 20,000 signatures so far, to ask the Ford Warriors in Pink campaign to add a metastatic breast cancer organization to their list of non-profit beneficiaries. They give prominence only to early stage organizations and to stories of “cure,” and on their panel of “warriors” they do not have any Stage IV stories.

I also contacted my mayor to ask why, since in the past she had lit City Hall in pink for awareness month, she couldn’t do the same thing for the approximately 40 thousand women and men who die from MBC every year, those for whom the pink of survivorship does not apply. She asked what our colors were, so I told her about METAvivor Research and Support, Inc., a group that concentrates exclusively on MBC and distinguishes the unique experiences of metastatic disease with a tricolored ribbon of pink, green, and teal. Success! City Hall was lit up in METAvivor’s colors for 3 days in 2012. Since then, METAvivor has started asking other cities to light up buildings in our honor.



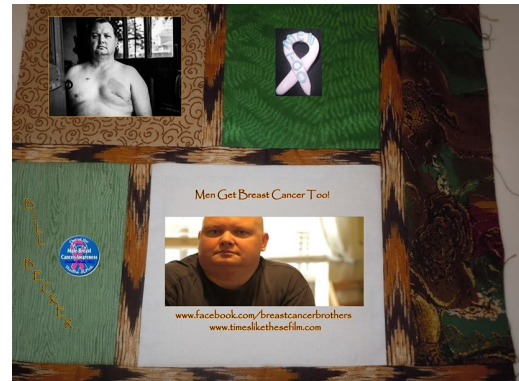
Our group also started a quilt project. We decided to make an 8½ square foot quilt with our stories sewn into it for display at hospitals, charity events, and fundraisers. I had never sewn before but ended up being the project manager, I guess because I was the healthiest member of the group. So far, my “mets” are stable, and I’m not on chemo. The quilt, now 75 percent complete, hasn’t been easy for this non-seam-

stress, but I’ve had a lot of help. I received fabric from Arizona; photo transfer paper from Washington; a display stand from Maryland; and fabric and stories prepared on iron-on transfer paper from London. Even women who were exhausted and dealing with chemo-brain sent in their stories. I edited them and posted them on our [Facebook page](#).

Some of the people taking part in the quilt project have already died but others, like me, are still alive and waiting for news of some breakthrough in cancer treatment—something that will prolong our lives. We

hold out hope. It is amazing when we receive stories from people even up to a few days before their deaths. They want their stories to be told.

Since the MBC community recognizes October 13th as Metastatic Breast Cancer Awareness Day, I would like to display the quilt in front of City Hall in Texas during the second week in October. The Bayou City Arts festival will be going on, along with the tri-colored lights of MBC awareness.



I wanted to tour the quilt before now, but I am no longer a “superwoman.” I am getting it done though. My metastisters and metabrothers are counting on me. In early September, the quilt, half done, made its way to its first stop, a metastatic breast cancer retreat organized by the Avon Foundation and John Hopkins University. The goal is to send it to as many research centers as possible so scientists will see the real faces and read the real stories of women and men struggling to stay alive on salvage chemotherapy. Sometimes when there is a will, there is a way.

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## **RESISTING BREAST CANCER CULTURE by Sarah Sutro and Judith Cohen**

*Sarah Sutro is an artist and writer whose work has been shown and collected in the U.S. and internationally. Judith Cohen is a writer with numerous publications and a college professor who teaches in an adult education program. They are close friends; both had been diagnosed with breast cancer.*

*A longer version of this article appeared in [The Intima-A Journal of Narrative Medicine, Fall, 2014 \(Columbia University Narrative Medicine Program\)](#).*

We are two friends, an artist and a writer, both who have recovered from breast cancer, who remain fit and healthy as we enter our seventh decade. Meeting over thirty years ago at an artist’s colony, neither thought about breast cancer as we hiked, talked and became close friends. Sarah, whose artist books reside in the Museum of Modern Art and Art Institute of Chicago libraries, as well as many other collections, had recently married, and was deeply involved in her art work. Judith was divorced and single then; her first novel (*Seasons*, 1984) had just been published. We have talked about our breast cancer experiences and treatment choices over the years, concluding that age affected how we felt about our bodies and self-image and hence our decisions about reconstruction.

## *Sarah's Story*

Sarah's diagnosis of cancer, in 1998, showed a tumor confined to her breast with no lymph node involvement, thus early stage. After a lumpectomy, the margins surrounding the removed tissue showed extensive 'in situ' (Latin for "in place") cells. Though classified as a non-invasive cancer (i.e., one that does not grow into normal tissues within or beyond the breast), she was advised to have a mastectomy, with the possibility of breast reconstruction.

At age 47, reconstruction felt like a positive new opportunity. She felt like she had her life ahead of her. She wanted to feel and appear as normal as possible, and to have an active life. Yet, having a major surgery was still a really difficult decision. Finally, after a friend showed Sarah her mastectomy scar, a gesture that was meant to be reassuring, she decided to have the reconstruction. The more she thought about mastectomy, the more she dreaded seeing a scarred chest for the rest of her life and feeling a loss of symmetry and balance in her body. Since many younger women were treated at this cancer center, Sarah felt confident about the outcome of her plastic surgery.

The type of reconstructive surgery used at that time was called a TRAM (Transverse Rectus Abdominis Myocutaneous) flap. In this procedure, which is no longer recommended or performed at many major



cancer centers, muscle is drawn up from the abdomen beneath the skin to fill the breast cavity. Slender and lithe, for Sarah it wasn't an issue of wanting to get a "tummy tuck" to get rid of belly fat at the same time as her breast surgery. She agonized about the decision for about a month after her initial lumpectomy, finally settling in on the TRAM flap. When she was in recovery after the surgery, Sarah remembers that her surgeon's 8-month pregnant belly pushing against the bed seemed like a sign of reassurance, that her own choice for reconstruction was one of hope, a positive expression of the future to come.

*"Raintree Series #11," 2006, natural color on paper, 31"x21".  
Natural color paintings reflect the wet, tropical environment of South Asia, its organic growth, movement and change, where Sarah lived for several years.*

Right after the surgery Sarah's chest wall felt like "wood," but after six months her body felt marvelously healthy and new. Mammogram technicians told her reconstruction looked natural. Curiously, the surgery was much less painful and disruptive than the CMF (Cyclophosphamide, Methotrexate, and Fluorouracil) chemotherapy that came later, a six month regime of pills and infusions that dragged on and on. Since the tumor was the infiltrating kind, and she was pre-



menopausal, she had the most aggressive treatment. Sarah's only regret about the surgery was that the scarring of her stomach muscles compromised her yoga practice: she had to do yoga on her own, at her own pace, and no longer in led classes.

Sarah later wrote a book about her experiences in Asia as an artist discovering natural colors, and touching on her experience recovering from cancer (COLORS Passages through Art, Asia and Nature, 2011).



*"Palm Lines," 2007, watercolor, 8"x11". The growth outside Sarah's windows in Thailand, huge palms, tropic weather and lush nature, inspired exuberant paintings as well as more minimal abstraction. Nearly ten years out from the experience of illness and treatment, life was good and to be lived.*

### ***Judith's Story***

Whereas Sarah felt youthful and wanted her body to reflect this after she was diagnosed with breast cancer, Judith was diagnosed with the disease later in life. Based on her family history of breast cancer, she considered having *both* breasts removed but decided against this when the results of genetic testing proved negative for BRCA mutations. Judith also could have chosen lumpectomy, with more surgery if needed, but she knew immediately that her preference was for the single mastectomy. "At that point in my life, I didn't need my breast to feel whole. I was 63 and my husband was very supportive." In other words, Judith believed that her self-image eclipsed others' perceptions of her body. As a feminist, she was also wary of the plastic surgery industry, breast enhancement and reconstruction. "Keeping the breast," she said, "gets far more attention than the cancer itself."

Despite her initial preferences, the decision making process wasn't easy. Judith talked to three other women who had had reconstructive surgeries, including one with compromised muscles, another who found it more painful than any of her other cancer treatments, and a third for whom the reconstruction failed. At the suggestion of her doctor she agreed to a consultation with a plastic surgeon, but she cancelled the appointment. One of her stiff-lipped New England students, whose mother had breast cancer, made an offhand remark that still resonates: "I think you should wear your scars proudly," she said.

Some mastectomy patients have artistic tattoos drawn on their bare chests. Judith chose a single mastectomy but opted out of the tattoos. Still wanting a way to gain acceptance of her new, different body, Judith instead took pictures of herself before and after surgery.



*Judith holds a mask over the breast that will be removed, anticipating its absence.*



*Though Judith normally didn't make visual art, she created a collage using pictures from different parts of her life, including pre- and post-surgery images. It continues to hang in her study*

Not only did Judith question the fetishizing of the reconstructed breast and the pink adornments that seem to accompany them, she was tired of all the books with affirmations about breast cancer being such a good thing. She came up with her own proposal. Reminiscent of Jonathan Swift's ironic solution to the "Irish problem" (his dead pan argument that all Irish children should be roasted or boiled to increase the food supply), she said: "If ALL postmenopausal women elected to have their breasts removed and it became as routine as getting a tonsillectomy or an appendectomy, wouldn't the breast cancer death rate decline dramatically?"

Judith's rebellious questioning of common assumptions remains intact. Despite years spent dreading breast cancer, her most powerful post-cancer realization is that millions of women face this disease, many emerging to have rich and interesting lives. She hopes we come to see breast cancer as a collective problem, like global warming. "It's a steep bump in the road, one deep enough to cause damage, but not a wall. For women with productive work and decent lives, having cancer need not push them off course."

Since Judith was diagnosed years after Sarah, she was grateful for her friend's support. Today they spend more time discussing art than they do cancer, but they are each helpful to the many friends and acquaintances who have also gotten a breast cancer diagnosis.

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### **STARTING A MOVEMENT: "THE RED STROLLER" by Belinda Silvestro**

*Belinda Silvestro is an environmental activist living in Brindisi, Southern Italy. With other women committed to taking action against the environmental pollution affecting her town and threatening the health of its inhabitants, she founded the association [The Red Stroller](#) (Il Passeggino Rosso).*

The summer of my mother's breast cancer diagnosis my father was recovering from a liver operation. I called my mother every morning to see how they were doing. It seemed like things were finally quieting down, but then my mother had a routine mammogram. Shortly after, I learned she had an aggressive breast cancer and was told that she had only one year left. I was shocked. My granddad died at 96; my grandma was 95, still alive and healthy. How could my mother die at 68? No!!!

My mother had surgery immediately. I was supposed to go to the hospital the morning after her operation, but I woke up I feeling really unwell and dizzy. I couldn't go. After she was admitted to a hospital for chemotherapy treatments, I couldn't visit her there either. The hospital was about 100 km away. I had two children to care for, and my husband worked in another town. Every afternoon I called my mother,

and she always said everything was okay. She never mentioned her pain. Between chemo rounds she spent more time cleaning than ever, as if she wanted to leave everything in order before she died.

Over a year my mother went through six different therapies, with no good result. She couldn't go out, so she used to tell her friends that it was because she didn't want to leave my father alone. She spent all day sitting in an armchair and had to hold onto a wall to walk. She hadn't hidden her illness, but she did conceal her suffering from me and her friends. When a dear friend of hers came to visit in October, my mother walked her to the elevator at the end of the evening without letting her know the gravity of the situation. I wanted to ask my mother many things, but I didn't really know the extent to which she understood the seriousness of her disease. I didn't know if I *wanted* to know how much she was aware of it either.

The previous summer, when we went to the beach, my mother wore a scarf on her head. We sat together most of the time, and as soon as she felt better she would talk to friends and swim. It was hard to imagine that she had only a few months. My mother died, as my brother - who is a medical doctor - had predicted, before Christmas.

Fifteen years have passed since my mother's death and still, as I tell her story, I'm crying tears I wasn't able to cry back then. I had been volunteering with an environmental association, working on environmental education with school children. Teaching them how to love and respect our environment and community helped me with my grief. But the more I studied and the more information I was exposed to, the more powerless I felt about the harmful choices local politicians had made, and were still making, when it came to the environment. I started to wonder whether there was a relationship between our environment and the people falling ill around me. I didn't know about any study that could confirm my impressions, but I couldn't help but see the patterns.

Brindisi is an industrial town with a host of environmental problems. Our territory is saturated with industrial installations, from coal-fired thermal, combined cycle and biomass power stations, to pharmaceutical and petrochemical industries, to hazardous industrial waste dumping, to landfills seized for contaminating ground-water. In 1986, Brindisi was included among the areas deemed "higher risk" for environmental crises and, in 1997, it figured among the areas of national interest for reclamation. Harmful substances in the air, water and soil have, both legally and illegally, altered the natural environment posing threats to the health of its inhabitants, including young people, children, the unborn, and those who will be conceived in the future. Brindisi is a town in desperate need of remediation and eco-sustainable projects. For all these things to be done, it needs its community involvement.

I felt overwhelmed and isolated. I wanted to fight for my community to improve our quality of life, especially for children because they are more vulnerable to the toxins produced by industrial pollution. But how? One day some young people asked me to sign a petition to reduce the amount of coal used in the local coal-burning power plant. I felt hopeful. Maybe I wasn't the only one in my community dreaming of



a better world; maybe it was possible to change things. I met some other women who wanted to protect the health of children; we got together, and *The Red Stroller* was born.

As women and mothers who care about the health of our children and of future generations, we believe we can avoid being simple bystanders as harmful choices are made in our community. To let people know what is going on and help them to get them involved, *The Red Stroller* formed to launch public initiatives in the streets, and to organize assemblies and conferences to engage the powers that be. The red stroller symbolizes the protection of children, red because of our alarm for their health put at risk from local industries, symbolized by the smokestack.



Using social media and other communication tools, we are building a national network of associations to protect the health of our communities and the environment. We petitioned for an epidemiological survey on the health of the local population and participated in a special council meeting on energy to express concern about the health of our community and to demand change. In addition to campaigning in our local area, we support other similar groups. Last year, we participated in public rallies in Taranto and Naples where people gathered to protest damage to the local environment in these two important Southern-Italian cities and its effects on inhabitants' health, especially children whose cancer diagnoses are on the rise. These initiatives aim to shed a light on the environmental impact on public health in Brindisi.

Studies recently published in international scholarly journals are starting to show what we already suspected. Researchers from the National Research Council and the local Healthcare Agency found that, between 2000 and 2010 the rates of congenital malformations in Brindisi were 17 percent higher than the European average, and the rates of cardiac congenital malformations are about 49 percent higher. The National Research Council also found an increase in the number of hospital admissions due to cerebrovascular, cardiac and respiratory diseases between 2000 and 2007, when the concentrations of specific atmospheric pollutants, though still within legal limits, increased in the area. Wind patterns seemed to direct the pollution straight from the industrial zones into the residential areas. Years ago, the head physician of the Division of Neonatology at Antonio Perrino Hospital in Brindisi, Dr. Giuseppe Latini and his colleagues had already found plasticizers from phthalates in breast milk and umbilical cords. Something must be done!

Like most groups, we face challenges. Many think the changes we are working toward are impossible to achieve in a society where industrial and political interests prevail. Women, too, are already busy with work and families, so it is sometimes hard to get them involved in political activities. Other problems we confront include the maintenance of productive interpersonal relationships within the group because

people have their own personalities and sometimes lose sight of what really matters. Without developing stronger working relationships with other local groups, because of disagreements or a different goals or intentions, we also risk weakening the social movement overall. Rather than organizing against multinational industrial corporations as small groups, we need a united front.

Our goals are far from being achieved, but we've made progress. The epidemiological survey we petitioned for has been approved. For our commitment to protecting the environment and raising awareness at the national level, *The Red Stroller* was awarded the Wangari Maathai Women, Peace, Environment prize on May 6, 2014, which was established by the association Southwards (A Sud) in collaboration with the Women's International House (Casa Internazionale delle Donne), and the support of the Commission of Women Elected at Rome Council. This recognition validates the importance of our work, and we hope it brings with it new opportunities for creating awareness and getting more people involved.



*The red stroller banner was hung at a street party organized by local associations, providing an opportunity for concerned people of Brindisi to meet up, share information, and draw attention to the cause. Watch a video of Passeggino Rosso Brindisi on [Youtube](#).*



## BIOGRAPHIES

JUDITH COHEN is a writer, and college professor, eight years past her breast cancer diagnosis. She teaches in an adult education program where adult's life experiences are central to the program. Her publications include: "Late for School: Stories of Transformation in an Adult Education Program," *Journal of Transformative Education*; "Python," *I Thought My Father Was God*, National Story Project edited by Paul Auster. Her novel *Seasons* was published by The Permanent Press of Sag Harbor, New York in 1984. Excerpts appeared first in Ted Solotaroff's quarterly, *The New American Review*. The book was originally published in German translation by Rowohlt of Hamburg as part of their international *New Woman Series* (1979). Cohen's short fiction has appeared in numerous magazines including *The North American Review*, *New Letters*, *High Plains Literary Review*, *Soljourner* and others. Her reviews and articles have appeared in *The Christian Science Monitor*, *The Dallas-Times Herald*, *The Boston Herald*, *The Boston Review*, and *The Women's Review of Books*.

ANA PORROCHE ESCUDERO PhD, a Breast Cancer Consortium partner, has an interdisciplinary background in social work (BA, University of Zaragoza, Spain), medical anthropology (BA, Barcelona University, PhD, Sussex University) and gender studies (MA, University of York). Her dissertation, "Political Narratives of Breast Cancer in Spain," investigated accounts typically excluded from public discourse and provides insight into the structural factors that shape illness experiences for Spanish women. Her most recent article "Perilous equations? Empowerment and the pedagogy of fear in breast cancer awareness" was published in *Women's Studies International Forum*. Currently, she is a research associate at the Division of Health Research at Lancaster University, working with inspiring colleagues from diverse backgrounds and affiliations to promote and deliver quality research on public health equity in the North West Coast of England.

CINZIA GRECO, a Breast Cancer Consortium partner, is a PhD candidate at the *École des hautes études en sciences sociales* (EHESS) and CERMES3 laboratory. She

already has degrees in Italian literature and Anthropology from the Universities of Salento and the University of Bologna in Italy, and in Gender studies from EHESS in France. Cinzia's interests focus on the interplay of body, gender and medicine. With a scholarship from the *Cancéropôle Île-de-France*, her comparative doctoral research, in France and Italy, explores the way patients and doctors view and manage post mastectomy breast reconstruction and cosmetic breast surgery.

NATASIA HAMARAT is a Belgian PhD candidate in sociology of health at the *Université Libre de Bruxelles*. For her master thesis, she explored how lay expertise on the body is produced and politicized in breast cancer patients' organizations in Belgium. She is presently starting her thesis focused on the end-of-life decisions in oncology, and especially on the decision of euthanasia.

GRAZIA DE MICHELE PhD is a Breast Cancer Consortium partner. An Italian-born researcher and historian living in the United Kingdom, Grazia was diagnosed with breast cancer at age 30 during the final year of her doctoral work. She had no family history of the disease or genetic predisposition. In May 2012, Grazia started the Italian blog *Le Amazzoni Furiose* (The Furious Amazons) to raise awareness among Italian women about the need to change the conversation on breast cancer and promote research into systemic issues contributing to the disease.

THERESA PALOMARES from Houston, Texas is a woman living with metastatic breast cancer. She is one of the initiators of the *Inspired Metastatic Breast Cancer Advocacy Quilt* and *METS Collage* project, whose aim is to raise awareness of the lack of research funding for stage IV breast cancer.

NINA REDL is a health care chaplain who has been working for many years with oncology patients. She tells the story of Natasha, a young woman with Inflammatory Breast Cancer that she met when she was working in the Middle East.

ASHLEY SAVAGE is a photographer whose work has been published and exhibited both in the UK and abroad. He collaborated with Tutu Tedder on the documentary photographic project they entitled, 'Cancer Sucks.' In line with Tutu's last wishes, he is looking for funding, publications and galleries willing to show this work. To view the complete photo series, visit the website, [www.savage-skin.co.uk](http://www.savage-skin.co.uk).

BELINDA SILVESTRO is an environmental activist. She lives in Brindisi, Southern Italy. With other women committed to taking action against the environmental pollution affecting her community and threatening the health of its inhabitants, she founded the association [The Red Stroller](#) (Il Passeggino Rosso).

GAYLE SULIK is founder and executive director of the Breast Cancer Consortium. She is a medical sociologist and independent scholar affiliated with the University at Albany (SUNY). Best known for her book *Pink Ribbon Blues: How Breast Cancer Culture Undermines Women's Health* (Oxford, 2011), she has also published articles, essays, and book chapters on medical consumerism, technology, cancer survivorship, health policy, interdisciplinary community research, and the culture and industry of breast cancer. She writes regularly for *Psychology Today* and other popular outlets and is currently working on a book on evidence-based medicine with Breast Cancer Consortium partner Bonnie Spanier. She is a sought-after media spokesperson on breast cancer, advocacy, and women's health. She has been a guest expert on NPR, CNN, AlJazeera, America's Radio News, Oprah Radio and other outlets, and is frequently quoted in publications such as *The New York Times*, *USA Today*, *Reuters*, *Los Angeles Times*, and others.

SARAH SUTRO is an artist and writer whose work has been shown and collected in the U.S. and internationally, including the library at Museum of Modern Art in NYC, the Johnson Museum at Cornell, the Harvard University Museums, the Boston Public Library Collection of Prints and Drawings, the Boston Athenaeum, Boston Globe, School of the Art Institute of Chicago and Sackner Archive of Concrete and Visual Poetry; and in Bangkok,

Dhaka, Belgrade, Montenegro, London and US. Awards include a Pollock Krasner Grant, Finalist for the Robert Frost Poetry Award, and residency at the American Academy in Rome. Her art can be seen at [www.sarah-sutro.com](http://www.sarah-sutro.com) and her recent book, *Colors, Passages through Art, Asia and Nature* about the use and discovery of natural inks, is available on Amazon. Her writing has been published in numerous magazines and books, including *Bangkok Blondes*, *The International Journal-Humanities & Social Sciences*, *Bangkok Big Chili*, *Art NE*, *Design Spirit*, and *Coping Magazine*. She has taught at over 10 colleges and universities, and was recently Visiting Professor at University of Massachusetts, Boston. She had breast cancer treatment 15 years ago.

STEPHANIE THEOBALD is a British journalist for publications including *The Guardian*, *The Sunday Times* and *The London Evening Standard*. She has also published four novels. Her third, *Trix*, about a road trip across America, was inspired by her close friend Tutu Tedder.