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17 Years Later, Stage 4 Survivor Is Savoring a Life Well Lived

By KATHERINE RUSSELL RICH

Each year on a day in January — the 15th, to be precise — I go to a [Web site](#) and post a message to hundreds of women I've never met, saying, essentially, "I'm still here."

Within days, a thunderous chorus comes back, 200 voices, 300. A few of them ask, "How can this be?" Sometimes they begin, "I'm crying." Many answer in kind: "I'm here, too. It's now three years." "Five years." "Three months." "Seven."

What we're doing, in a way, is checking for lights in the darkness.

Now there probably aren't a lot of Web sites where the announcement that you're around and breathing would cause anyone to take notice, let alone respond. But this is a site for people with Stage 4 [breast cancer](#), something I've had for 17 years. The average life expectancy with the diagnosis is 30 months, so this is a little like saying I'm 172 years old: seemingly impossible. But it's not. I first found I had the illness in 1988, and it was rediagnosed as Stage 4 in 1993. That's 22 years all together, which is the reason I post each year on the anniversary of the day I learned my [cancer](#) was back: to let women know that it happens, that people do live with this for years.

I tell them that when the cancer returned, it came on so fast, spread so quickly, that I was given a year or two to live. Within months, the disease turned vicious. It started breaking bones from within, and was coming close to severing my spinal cord.

Nothing was working, till a doctor tried a hormone treatment no one used much anymore, and the cancer turned and retreated, snarling. It remains sluggish but active. Every so often, it rears its head; when it does, we switch treatments and it slides back down. In that way, I stay alive.

I tell them: you just don't know.

Two and a half years after the Stage 4 diagnosis, I confessed to my mother that the doctors had said I had two years to live, tops. I'd kept this information to myself because if you say it, it's true. I told her this laughing, as if we were trading preposterous stories. "Well, I guess you're going to have to hold your breath if you're going to make that deadline," she replied, in her slow Southern drawl when I gave my previously stated expiration date.

I spent the next five years holding my breath, then did the same for another five. I enacted every New Year's resolution, past and future, all at once. Quit work that had grown stale and became a writer. Wrote a book. Went to India on assignment, fell in love with the language that was swirling around me, went back to live for a year and learn Hindi. Didn't realize the reason I'd come to dislike that hyperbolically overachieving [Lance Armstrong](#) was that his behavior was too familiar. *Take a nap, Lance!* I'd think to myself, though in truth I couldn't either.

But if I was verging on radical levels of life consumption, I had a reason: No one had told me I wasn't going to die soon.

About 12 years out, my doctor finally did.

There's a small subcategory of people with Stage 4 breast cancer, it turned out, who live for years and years. "Twenty. Thirty," said my doctor, George Raptis. This group constitutes about 2 percent of all cases. Doctors can't predict who will fall into this category. They can't say you're in it till you're in it — till you've racked up the necessary miles.

The reason they can't is that for all the pink-ribbon hoopla, despite the hundreds of millions that have been poured into breast cancer research, hardly anyone has looked into the why of long-distance survival; not one doctor has specialized in this field.

Here's pretty much the sum of collective knowledge: People in this group tend to have disease that has spread to the bone (as opposed to lung or liver, say) and feeds on [estrogen](#). They tend to do well on hormone treatments. End of commonly known story.

But as Dr. Gabriel N. Hortobagyi at [M.D. Anderson Cancer Center](#) in Houston told me, you can also find women whose breast cancer spread to organs other than bone, for whom hormone therapy did exactly nothing, who had their lesions surgically excised and who have been free of cancer for 30 years. None of these women could have expected to live.

You just don't know, and neither, unfortunately, does the medical field.

One reason, as the breast surgeon Dr. Susan Love told me, is that "many clinical trials are funded by the drug companies to run for five years," obviously not enough if you're investigating long-term survivors. But through her institute, the [Dr. Susan Love Research Foundation](#), she has begun to

conduct research.

Dr. Love said she was inspired by a colleague who told her that in World War II, aviation experts focused on planes that went down until someone said, “Why aren’t we studying the planes that stay up in the air?” By no means a reflexive optimist, she thinks there’s hope we’ll find a cure.

On the Web site, I tell the women how deeply I believe there’s no such thing as false hope: all hope is valid, even for people like us, even when hope would no longer appear to be sensible.

Life itself isn’t sensible, I say. No one can say with ultimate authority what will happen — with cancer, with a job that appears shaky, with all reversed fortunes — so you may as well seize all glimmers that appear.

I write to them (to myself) that of course this is tough: the waiting to see if the shadows are multiplying, the physical pain, the bouts with terrible blackness.

“But there can be joy in this life, too,” I say, “and that’s so important to remember. This disease does not invalidate us. This past year, I’ve had the joy of falling in love with my sister’s kids, who live states away and whom I hadn’t had the chance to know. I’ve had a second book come out, one I worked on for eight years, about going to live in India with Stage 4 cancer. I’ve had so many moments of joy this year, but when I’m in blackness, I forget about those.” Then I ask them to write and tell me about theirs, and lights begin to flash.

“Had a pajama party with my oldest friend, laughing through the night in matching pajamas about old times.”

“Came in second in a bridge tournament.”

“I went on a wonderful camping trip with my family.”

“Seeing my older daughter grow taller than me. She’s now 5-9.”

One thing I don’t ever think to say: When I was told I had a year or two, I didn’t want anything one might expect: no blow-out trip to the Galápagos, no perfect meal at [Alain Ducasse](#), no defiant red Maserati. All I wanted was ordinary life back, for ordinary life, it became utterly clear, is more valuable than anything else.

I don’t think to say it, and I never will. The women on the site already know that.

Katherine Russell Rich is the author of “Dreaming in Hindi: Coming Awake in Another Language” and “The Red Devil: To Hell With Cancer — and Back.”