BREASTCANCER HANDBOOK2000

The **New** Survivors

They're in their 20s and 30s, and already a battle with breast cancer is behind them. Now, their biggest challenge is what lies ahead

BY JUDITH NEWMAN

"YOU'RE TOO YOUNG!" ASHA CLAYTON-Niederman could still hear the stunned disbelief in the voices of family friends some of them doctors—after she told them she had breast cancer. Who gets breast cancer at 24? "Well...I do," she said.

But Clayton-Niederman wasn't going to become bitter. "There was no sense in moping around," she says. "I wanted to be in control." After her first round of chemo, the Boston violist got together with a

friend to shave off her hair—and take photos of the process.

Listen up!
Do your BSE this month.
Please.

Vhoopi
spears Pout

This message is addressed to anyone with breasts. We all know women-friends, relatives, coworkers—who have been affected by breast cancer; some survive it, but others do not. Now, we must find a way to make survival the rule, not the exception. The key is early detection—and the first step is breast self-exams (BSEs).

I've always done them. My mother was a nurse, and she taught me that there is no shame in talking about taking care of ourselves. I was able to teach my daughter to do BSEs, and I'm confident she will pass what

First, she cut it into a mohawk— Click! Then two devil's horns.

Then one horn, then a full shave. It was a defiant gesture. But Clayton-Niederman was still facing major unknowns. "People talk about a five-year survival rate, but that gets me to what, 29?" she says. "Tell me I'll be here when I'm 60 or 70 or 80!"

WHAT? I'M NOT IMMORTAL?

Every woman who gets breast cancer

is forced to look death in the eye much too soon. But for women in

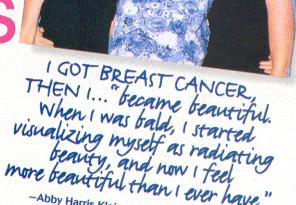
she's learned on to her daughters.

But not everyone finds BSEs easy. Often, one thing stands in our way: fear. We let myths like "It's going to hurt" and denial tactics like "I don't want to know" keep us from performing BSEs,

getting mammograms and seeking medical advice. We need to set aside these fears—especially those that lead us to believe that every lump is a hospital sentence—and move on.

Start by talking to your daughters, sisters, mothers and friends about how to examine themselves. If they have questions, there's a ton of information out there—and in this handbook. Check it out. Please.

Whoopi Goldberg, a spokeswoman for imammogram.com, is an executive producer of Strong Medicine on Lifetime Television.



—Abby Harris Klein, 35, Oakland, California (left), with friends Leslie — Heckenlively and Lore Hogan

their 20s and 30s, who are just beginning to establish their own lives, the diagnosis can seem an especially cruel blow. "Very suddenly, you go from thinking of yourself as someone who is going to die someday to someone who could perhaps die the next day," says Meg Sweeney Lawless, a New York City comic who was diagnosed with breast cancer when she was 33.

Aquatia Owens, a New York financial planner diagnosed at age 31, puts it this way: "I don't want to say this was worse for me than for someone older. Everyone wants to live as long as possible. But at 31, you still think you're immortal—and then you find out you're not. You won't get to look back at what you had. You look forward to what you may never have."

Breast cancer is particularly lethal in the young—in fact, it's the leading cause of cancer deaths in women 20 to 39. For one thing, everything in the body grows more vigorously before menopause, including cancer cells. Moreover, young women with the illness are more likely to have one of the two genetic mutations experts think make tumors more lethal. Plus, the disease has often become advanced by the time women this age are diagnosed: Some doctors simply don't suspect breast cancer in women so young.

But frequently, it's not the diagnosis that delivers the most devastating blow for a breast cancer patient under 40, but treatment—and its detrimental effects on fertility. "The first question (Continued)

a young cancer patient asks her doctor is, 'Am I going to die?' And very soon after that: 'Will I be able to have children?'" says Lauren Bisk, Psy.D., a psycho-oncologist at St. Vincent's Comprehensive Cancer Center in New York City, who specializes in treating the emotional difficulties of cancer patients.

"When I asked about having a baby, one doctor told me not to even think about it," says Lori Kennedy, a sales executive from Weehawken, New Jersey, who was diagnosed at 29. (There's some evidence that the abundance of estrogen in the body during pregnancy might cause stray cancer cells remaining after treatment to grow.) "I broke down and sobbed," she recalls.

Luckily, the "no children ever" stance is rapidly changing in the medical community and, in fact, once Kennedy reached her five-year survival mark, she and her husband decided to try for a child. In 1998, she gave birth to her daughter, Peyton. (Both are healthy.)

But wrenchingly, chemotherapy sends many women into menopause, taking away from them the decision to have a child. "That was the most devastating aspect of cancer to me," says Mary Katzke, a filmmaker from Anchorage, Alaska,

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I GOT BREAST
CANCER, THEN I...
"worked with a
surrogate to have my
son, Corin, who is
now II months old."

-Mary Katzke, Anchorage, Alaska

diagnosed in her mid-30s. "I could deal with the body image, the hair loss," she says. "But I always wanted to be a mother. When I found out I had cancer, it was like I was playing musical chairs, then all

of a sudden the music stopped, and there were no chairs left."

Katzke built her own chair: Before she started chemo, she had four of her eggs fertilized and froze the embryos. When she reached the five-year survival mark, she found a surrogate mother to carry one of them to term. Last year, her son, Corin, was born (that's the two of them below).

DATING A "CANCER CHICK"

For some single women, the question of getting pregnant is an issue to face only *after* they've cleared the dating and marriage hurdle. Lisa Frank, 38, had never had much trouble with relationships—until she was sidelined by a lumpectomy, chemotherapy and radiation in 1998. "I started chemo in October, and I met this guy on New Year's Eve," says the New Yorker. "I wasn't drinking, and he

was razzing me about it. Finally I blurted out, 'Look, alcohol doesn't mix well with chemotherapy.' That stopped him in his tracks." Lawless, the comic, approaches the subject of dating with her trademark mix of insight and biting humor: "I don't think having cancer keeps you from dating, but it raises the stakes. It's hard to goof off and just go on a date for fun," she says. "People tend to be real serious in the beginning: 'Oh, man, I'm dating a cancer chick! Better make it fun, it may be her last time!""

THE INFORMATION VOID

Getting dates is one thing. Getting relevant information about your illness is another entirely. Not all that much is known about breast cancer's course in premenopausal women. And no one, not even the experts, can tell women what to expect after they've reached that magic five-year milestone. "Studies look at five- and 10-year survival rates," says Cynthia Rubin, president of the Young Survival Coalition (www.youngsur

I GOT BREAST CANCER,
THEN I... "made peace
with my estranged brother after
a 10-year separation. I
finally know how to let go of the
past and live for today."

—Cheryl Ryan, 39, Crested Butte, Colorado

vival.org), who was diagnosed last year at 36. "We want to know the efficacy of treatments 30, 40 and 50 years out. Yet we're told it's very difficult and expensive to follow people that long."

"You read all these books, and they all give studies on postmenopausal women," says Aquatia Owens. "So all the results have nothing whatsoever to do with you. For young women, our only research is trial and error on ourselves: What worked for her? Let me try that."

Luckily, there are more ways than ever for young women to get that crucial woman-to-woman advice: Support groups specifically for women under 40 have begun to form around the country. (In New York City alone, at least four have been started since 1998.) The women consult each other on how to cope with early menopause. They share the reality that breast cancer—and fear of it—will be with them for years. And they glory in each other's determination to face that fear head on. "Before you get sick, you don't think life will be any other way than the way you dreamed," says Owens. "I'm 35. If I live to see 60, I'll be beside myself. Because I can get a lot of things done between now and 60."

Asha Clayton-Niederman's getting things done, too-breast cancer be damned. It's been almost a year since her diagnosis and treatment—lumpectomy followed by chemo and radiation—and she's slowly becoming "just another girl" again. She went on a bike trip through Italy with her family. She's started dating a nice guy. "When I met him," says Clayton-Niederman, "my hair had just started to grow back. He came up to me in a bar and said, 'I have to tell you, I love your haircut. How did you have the guts to cut it so short?' And I said, 'Well, you know, it's a long story. I'll tell you sometime."

Additional reporting by Donna Fennessy