# THE FUTURE COULD BE

One young woman struggles with the choice: to know or not to know?

By Leah M. Charney

y mom doesn't have breasts. Hers were removed when she was 39. I was 12 years old when they disappeared. Just as I was getting my breasts, hers were being taken away.

The American Cancer Society estimates that there will be 192,370 new cases of breast cancer in 2009. About 10,000 of these women will be under the age of 40.

And according to the National Center for Health Statistics, approximately 78,000 women will get a mastectomy this year, a procedure in which all of the breast tissue from one or both breasts is completely removed. In 2008, the American Society of Plastic Surgeons performed 11,327 breast reconstruction surgeries on women under the age of 40.

Most of these surgeries were performed on women with cancer, but several thousand of them may have been performed on women with perfectly healthy breast tissue.

My breasts are not victims
— not yet. They are a source
of power. Ultimately this is
why it is so hard to imagine



a me without them. Some women whose relatives have been so plagued by breast cancer, like mine, choose tests, surgeries — various preventative measures to try to army up against future cancer cells. They find strength in sort of scientifically foretelling their breasts' future. But for other women — for me — it is not that simple.

This month I will be 26 years old. This month I will have a mammogram — again. I was 20 when my

tender, terrified bosom was first placed between those cold plates. I'd like to say the mammograms get easier; they haven't yet. In fact, each one becomes more of an event. Will this be the time they find cancer?

But my biggest fear isn't actually getting the cancer that has plagued my mother so many times in her almost 53 years. My biggest fear is simple: Who will love me if I don't have breasts? More importantly, will I love me if I don't have breasts? For me,

they are a key part of what makes me beautiful; what makes me a woman. Without them would I be less beautiful? Less of a woman?

ask this question of my friends, my family, my boyfriends. One night, my mama and I are holding court, as we often do. I am outside on the porch in the sticky summer air. My cell phone is hot to my face and tears burn my cheeks. I call terrified or sad or angry, and she listens like all moms should.

"There is some beauty in cancer," she says on this particular night.

This woman is an incredible, beautiful soul. She is bold, kind, gracious, feisty. In short she is the older, blonder version of me. And this I am deeply proud of. But she is a double amputee. Her breasts, once removed, were never reconstructed. Currently she is living with terminal cancer — a reoccurrence of the breast cancer that has taken hold in her lymph system since there is no more breast tissue to gobble up. I have promised her that if she lives to be 60 I will take her to Greece and buy her

# BEAUTIFUL

new breasts. I cannot look at her scars.

Two big anchor scars sit atop her chest where her 36-C cups once lived. They are surrounded by pockets of flesh and fluid. They are not pretty.

So what is this beauty in cancer? Apparently the things you discover in yourself. When her cancer returned in August of 1999, my mom packed up herself and her life and started over. She left my dad. She went back to church. She changed careers. She fought for her life. She created a new life worth fighting for. She made new friends. She created valued relationships with her children.

"I understand the fear of what-if, baby girl, but if you never open up and try, you miss out on all the good stuff," Mama says sagely.

The first time I found a lump I convinced myself I was making it up. When you're constantly waiting for cancer, looking for cancer, then everything could be cancer. So I decided I was imagining the lump until a week later when my doctor also felt it during my already scheduled yearly exam. But two ultrasounds later it was gone. It was nothing. This time.

watched cancer tear my parents apart.

And while there were certainly other factors in the demise of their marriage, the cancer was a big contender. My dad couldn't fix it and my mom didn't want him to. From the perspective of a child it appeared as though each sickness pushed them further and further apart. And once her breasts were gone, he was even more different and distant — to all

of us.

I can't imagine what it must be like to watch your partner fight cancer, have chemo, lose body parts. But I know the possibility of this scenario affects my own romantic relationships. By date three, most people are thinking, "Do I want a date four?" Or maybe "Could I introduce this person to my friends?" Or "What does this person look like naked?" But not me. Date three I've been known to think, "Could I be sick with you? Are you the kind of person who can handle it?" Which is the saddest thing I've ever had to admit.

Jenny Atchley, of Erie, is 29 years old. Two years ago she had a tumor the size of golf ball removed from her colon. Last year she had her breasts preemptively removed, and in January she finished her reconstruction. We meet in a bar and bond

over a glass of wine. We have this secret in common: this fear of what our bodies will do without our permission.

"Even after being married six years I was still afraid if my husband would still find me attractive," Atchley confides when I start poking around about her surgery.

So what makes a woman decide to chop off her breasts before they turn cancerous? Knowledge. After Atchley's bout with colon cancer, she was tested for genetic mutations and that test made her decide to, in her words, "Flash the threat of breast cancer a defiant middle finger."

I, too, could end some of the guesswork. Doctors have suggested more times than I can count that I have genetic counseling. Two genes — BRCA1 and BRCA2 — have been identified as genes that, when they mutate, increase risk for breast and ovarian

cancers primarily, and also certain small bowel cancers and prostate cancers.

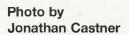
For \$3,120 the people at Utah-based Myriad Genetic Laboratories will do a full sequence genetic test that searches for these mutated genes.

According to Myriad, "Women with a BRCA mutation have a 33 to 50 percent risk of developing breast cancer by age 50 and a 56 to 87 percent risk by age 70." Not done scaring their captive cancer-afraid audience, the statistics continue: a 27 to 44 percent chance of developing ovarian cancer by age 70.

Perhaps that range seems awfully wide, and age 50 seems pretty far away. But my mom had ovarian cancer at age 30 and breast cancer number one at age 33.

've avoided having the testing done for a few reasons. This test could determine whether I have positive genetic proof, this mutation, a so-called "cancer gene." But I don't really want to know. What does knowledge get me? Is it power in this case?

Atchley had the test done and tested positive for a mutation to BRCA1. To paraphrase one doctor, I will get a mammogram and an MRI each year, six months apart, due to family history. And if I get the BRCA1 and BRCA2 tests? I'll still get the mammogram/MRI one-two Continued on page 22



Hair and make-up by Angel Garcia, www.pinupprettymua. com



Continued from page 21 punch. For the rest of my life.

Plus, testing positive for the genes delivers more decisions. Another Myriad pamphlet shows a graph with cancer prevention management options.

Go on a drug like Tamoxifin, which interrupts estrogen production, and breast cancer risk may decrease as much as 49 percent. But no estrogen equals early menopause for as long as the drug is used.

Have an oophorectomy (removal of the ovaries) and the risk could drop 53 percent for breast cancer and 96 percent for ovarian cancer. But no ovaries equals no biological babies.

And most importantly (to me and my breasts, anyway) have a prophylactic mastectomy (removal of the breasts) and breast cancer risk could drop by 90 percent. But no breasts brings me right back to square one.

I'm overwhelmed by the numbers and the options, and I tell Atchley that I'm terrified to have the test because I'm not ready to make the decisions that come with a positive result.

"It's one of those things

where there is no turning back," she explains, understanding. "I have had moments over the last year where I wondered if I wanted to know all this."

Kindly, Atchley and I retreat to a dark bathroom stall where, like a teenage boy, I fumble over her new breasts. They feel natural. They look right and hang the way a 29-year-old woman's breasts should. I would never know they weren't the ones she came with, except for one pink telltale scar that runs from the side of her nipple to her underarms.

She looks beautiful, womanly.

o do I want to know about BRCA1 or its evil twin BRCA 2?

Can I work through my fear with my therapist? Ride my bike? Eat a healthy diet? Not smoke? Get a mammogram? Six months later get an MRI. I'd rather keep my breasts. These are mine. I like the ones I came with.

I consult Timothy Rebbeck, a researcher at the University of Pennsylvania. Rebbeck is working on a study, funded by the National Cancer Institute, looking specifically at measuring the risk reduction BRCA-positive women receive by getting mastectomies.

"It's pretty clear now that testing for BRCA1 or BRCA2 has value because you can do something to reduce cancer risk and mortality if you are found to be positive," Rebbeck says.

He's onto something there. I live in fear of what the test will tell me, but that is a bit like sticking my fingers in my ears and screaming "la-la-la-la-la." So let's say I do get the test. And then let's say the test is positive.

Then what?
Rebbeck explains,
"Prophylactic mastectomy
is not necessarily
recommended but is an
option. Since there are other
preventative options for
breast cancer ... the need for
mastectomy for prevention
is less, and the psychological
issues are potentially more
complex."

Definitely more complex. I won't get a simple test because if it's positive then I'll have to decide whether or not to have my breasts removed and reconstructed, and if I have them removed and reconstructed if I can have a successful romantic relationship. I'd say that's pretty complex.

Oddly, I begin to feel at peace with the idea. This test is something I've avoided for years, blamed for my lack of commitment in relationships, hid behind. It is long past time to stop hiding, stop fearing the what-if. Maybe it's time to get the test now and worry about the results later.

Psychologist Elizabeth Lombardo says it's OK to be scared, but not if that fear prevents you from making informed decisions. Lombardo, based in Pennsylvania, has been on CNN and quoted in Newsweek, Self and Glamour, among others.

"There is a difference between avoiding testing out of fear," she says, "and consciously and rationally deciding not to get tested."

o, consciously and rationally do I want this test?

The test could

The test could provide answers. Or more questions. And frankly, if I decide not to get the test will I be able to stop worrying? I may be afraid of a day that never comes. My mother's legacy need not be mine. She was right to tell me that concentrating so furiously on a what-if makes me blind to the beauty around me. What if I spend all this time scared, preparing for a diagnosis that never comes?

I never used to be afraid. And so what if this is just a phase? I could grow out of it. Each clean mammogram, each clean MRI, reinforcing my health. My pert breasts reinforcing their beauty, their strength, reinforcing me.

Kate Crow is a master's level genetic counselor in southern Colorado.

"Genetic tests are not the Holy Grail for medical management decisionmaking," she says, getting to the root of my problem. "Surgery is always an option, not a requirement if you have an inherited risk for cancer."

Right. Option. Not requirement. I forget that sometimes.

But here is my hope — and yes, there is a lot of hope in cancer, as my mom *Continued on page 23* 

# Around town

Here are some local plastic surgeons who do prophylactic mastectomies, according to the American Society of Plastic Surgeons:

Claude Burrow, of Boulder — 303-449-5822, www. drburrow.com

Winfield Hartley and Hans Kuisle, of Boulder — 303-443-2277, www.boulderplasticsurgery.com

Glenn Herrmann, of Louisville — 303-664-9400, www.herrmannplasticsurgery.com

Scott Replogle, of Louisville — 303-666-4554, www. replogleplasticsurgery.com

Jeff Swail, of Longmont and Boulder — 303-449-6666, www.bvplasticsurgery.com

hen was the last time that you took a long, hot bath, surrounded only by silence and a few candles? Or the last time you hiked solo into the mountains? Or went on a retreat with your best friend?

No matter what the occasion, you probably have a particular feeling rise up when you think about these kinds of events in your life. A feeling of deep relaxation. Of relief. Of expansion. Of gratitude.

These are the experiences — the rituals — that have the potential to play a powerful role in our lives. To help us move through tough times, to lift our spirits when we are low, to shift our vision and invite us to celebrate the beauty of life.

### What it's all about.

Ritual doesn't have to be about spending lots of time or money (though a weeklong guided trek through the mountains of Peru might be the perfect thing for you, if you can swing it). It is the intention of our ritual that gives it its power. Create a ritual that has meaning, and it can transform the most overwhelming emotions and

Step into the ritual of dance every week with Kimberly Jonas. BodyMantra classes are held at Core Movement Studio, 1844 55th St., Boulder; 6-7:30 p.m. Wednesdays and 10:30 a.m.-noon Saturdays. Check out www.body-mantra.com.

experiences.

Beware the urge to make your rituals about achieving a particular outcome. Ritual is not always about moving in a straight line between point A and point B. On the contrary, conscious ceremonies and rites require that we remain open-minded so that we can welcome new viewpoints and unexpected insights. In order to open fully to the power of your intention, be willing to accept an outcome that you never expected.

This isn't always easy stuff. Yes, it would be fantastic if we could create a bubbling, witch's brew on the night of a full moon, utter a few Shakespearian invocations, raise a hand to the sky and — poof! — everything has changed.

But the reality is that diligence is often a requirement when ritual is involved. We must stay attentive to our process and build from a foundation of faith so that the hidden wisdom can emerge.

Start with the obvious.

There is probably something happening in your life right now that jumps out as being a drain on your energy. Maybe you are staying up late every night, working. Or recovering from a painful divorce. Or battling an illness. This is the inspiration for your ritual. By rallying around a particular event or circumstance, we consciously invite transformation.

# Ritual can take many forms. If it is a new concept for you, start simply:

- 1. Take a slow walk around the block at the end of the day, taking time to acknowledge five things that you are grateful for from that day.
- 2. Take a bath, complete with your favorite music and scents; set the intention for your worries and sorrows to slip silently into the water.
- 3. Invite your three dearest girlfriends over to share a

meal and to speak why you are each so important to one another.

4. Choose a yoga or other movement class that allows you to joyfully relate to your body for a couple of hours.

The key is to weave specific purpose and action together. Alone, the hot bath, the walk, the voga class are absolutely helpful. However. invoking your most heartfelt intention into those activities will magnify their potency.

When it comes down to it, rituals ask us to enter an altered state - one step or many steps removed from the bustle and schedule of daily life. Through our own private ceremony, we invite a modified view of daily events, balancing pointed, clear intentions with a healthy dose of surrender. We have to simply open to the powerful magic of these rituals to discover new pathways for ourselves and endless beauty along the way.

— By Kimberly Jonas Jonas is a Boulder-based intuitive guide and healer and teacher of sacred movement. yoga and meditation. Contact her at www.body-mantra.com or www.kimberlyjonas.com.

## Continued from page 22

has shown me. I am not my mom and my future man will not be my dad. On her own journey, Mama found beauty in independence and solitude. I seek beauty in allowing myself companionship.

I want to fall in love with a man who loves me. A man who will look past the statistics and the percentages and

### QUOTE OF THE MONTH

"When you have only two pennies left in the world, buy a loaf of bread with one, and a lily with the other."

- Chinese proverb, on beauty

possibilities. A man who will love my breasts and think them beautiful. A man who would also throw them a funeral if they are taken away. (Atchley's husband did that for her.) A man who will throw them

a parade if they are rebuilt. A man who is able to look past cancer and still see me. In short, he must be braver than I am.

I still don't know if I will have the test done. But what I do know is being

afraid of a test is a waste of my time, my youth - and my beauty.

### A look ahead:

October is National **Breast Cancer Awareness** Month! Look for special features in next month's Women's Magazine.

Check out www.nbcam. org for information on breast cancer detection. testing, support and events.