

## **Not-So-Vital Statistics**

How much do you really want to know?

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My daughter looked beautifully translucent on the ultrasound, a diaphanous form twisting and kicking on the grainy screen. The obstetrician slid the wand up and down my abdomen, pausing to point out the tiny kidneys, the heart-shaped brain, the pearly links of spine. You can see quite a lot by ultrasound these days, but of course you can't see everything. Still, I started breathing normally when the four chambers of her heart came into view, beating regularly, perfectly formed.

We did the scan at 22 weeks, late by anyone's standard. So late that if we found anything seriously wrong, we would have little time to debate. I knew we were taking a risk. My husband and his parents had urged me to undergo amniocentesis but I begged off, claiming I was scared of the small chance, at age 32, of miscarrying from the procedure. I didn't tell them about my other fear, the one that year after year keeps me from letting anyone perform genetic tests on me: The very real possibility that a doctor will peer into my innermost machinery and discover something wrong.

There is, most likely, an aberrant piece of DNA on my mother's side of the family, a microscopic culprit that gives some of us colon cancer and attacks others in the breasts. We don't know much about it. It may or may not be linked to BRCA1 or 2, may or may not be visible to the human eye, lies in wait for about 40 years and is probably a dominant gene. And if all this is true, said the medical geneticist who analyzed my family tree, there's a 50-50 chance that it resides in me.

"Don't you want to know?" physicians and friends have asked.

Of course I do. Of course I don't.

Unfortunately, a test can't keep me from developing the breast cancer that killed my mother at age 42 or appeared in her sister at 45. It can only tell me the likelihood it will. And even if I test negative for a BRCA gene, no one can promise I'll never get the disease. At best, I've realized, a test would remind me to keep getting regular

mammograms and doing monthly self-exams. At worst, it would make me spend every waking minute poking and prodding my breasts, waiting for a lump to appear.

When I decided against doing genetic tests on my daughter, I wasn't worried about overlooking a gross defect, which would probably show up on an advanced ultrasound. I was worried about discovering a small abnormality like the one I might have, the kind that could allow her to live symptom-free for 30 or 40 years. The kind that might make a prospective parent stop and think. And I couldn't help thinking, what if someone had offered such a test to my grandmother and discovered my mother's faulty gene? What if someone had suggested that my mother, while pregnant, do a genetic test on me?

I know the disease that killed my mother could already be starting to multiply inside me. Yet here I am, laughing on the telephone, having lunch with friends, writing books, making love. I have had 33 good, healthy, productive years. It would have been a tragedy to have missed them. You can do quite a lot with half a lifetime. Do I—does anyone?—have the right to determine the worth of someone else's in advance?

My daughter was born early one morning in October, nine and a half pound of normal, screaming baby, 10 perfect fingers, 10 tiny toes. I can see that her eyes and ears work fine, that her motor development is on schedule, that she breathes steadily through the night. But of course, I can't see everything. If one day, years from now, she decides to find out if she carries a gene that increases her risk of developing breast cancer, I'll support her right to make that choice for herself. Until then, I'll hope that in addition to whatever genetic material I may have given her, I'll also pass down my commitment to breast cancer activism, my belief in early surveillance, and my never-ending hope for a cure.