Family Matters
By Bonnie Rochman

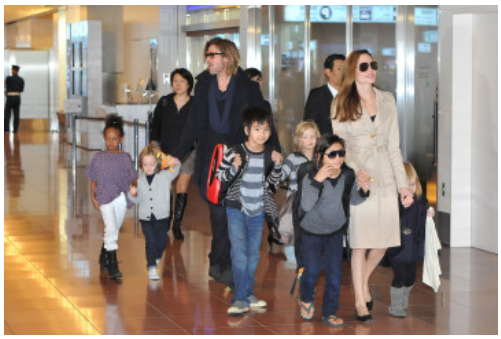
KIDS AND DNA

Hard Choices Angelina Jolie Faces About Testing Her Kids for Breast Cancer Genes

The actress made the difficult decision to remove both her breasts before she developed breast cancer, but her genetic makeup means her children may be at increased risk of the disease as well.

By Bonnie Rochman @brochman | May 14, 2013

Most women who get breast cancer each year have no family history, but Angelina Jolie's story was different. Her mom died at age 56 of ovarian cancer, a related disease.



Jun Sato / WireImage

Angelina Jolie and Brad Pitt with their kids in 2011

Doing her best to make sure that her own six kids don't lose their mother to breast cancer motivated Jolie to have a preventive double mastectomy, a process she revealed in a bold and candid op-ed in Tuesday's *New York Times*.

> We often speak of "Mommy's mommy," and I find myself trying to explain the illness that took her away from us. They have asked if the same could happen to me. I have always told them not to worry, but the truth is I carry a "faulty" gene, BRCA1, which sharply increases my risk of developing breast cancer and ovarian cancer.

As a BRCA1 carrier, Jolie stands a 50% chance of having passed the faulty gene to each of her three biological children. While that possibility can provoke tremendous anxiety in parents, most experts don't recommend childhood genetic testing for diseases like breast cancer that don't often affect young children. "In a typical situation, most people would counsel her to wait until her biological children are mature adolescents or young adults before discussing this with them," says Dr. Robert Green, a medical geneticist at Harvard Medical School. "But given that she's a public figure, it's going to be harder to shield them."

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In February, both the American Academy of Pediatrics (AAP) and the American College of Medical Genetics and Genomics (ACMG) recommended against testing a child for adult-onset diseases such as breast cancer. However, the experts who developed the statements told TIME that if parents insist on testing their kids, they should be allowed to proceed:

> While the earlier statements from the AAP and ACMG firmly advised against genetic testing in

children to determine future risk of disease, the updated policy acknowledges that parents are the ultimate decision-makers when it comes to childhood-onset conditions. Predictive genetic testing for adult-onset conditions is still strongly discouraged, but in rare cases, if the parents are in agreement — and, ideally, the child is old enough to concur — testing can be ordered.

"If the family truly believes this is what's best for the child, we need to respect that," says Dr. Lainie Friedman Ross, a professor of pediatrics and clinical ethics at the University of Chicago and the statement's lead author.

Historically, the medical community has been reluctant to test kids for fear of causing psychological harm: could the knowledge that kids are going to get sick affect family bonding? Would mom and dad treat the affected child differently from his siblings or fall into the trap of the "vulnerable child" syndrome, becoming so nervous about a child's health that they don't let him out of their sight? "We still worry about that, but we've come to realize to the extent that there are data that the concerns were probably over-hyped," says Ross.

The rationale behind not testing kids for breast cancer takes into consideration that many adults who suspect they may have a BRCA1 or BRCA2 mutation — two known gene changes that increase the likelihood of developing breast and ovarian cancer — ultimately decide not to get tested. "There is a long-standing consensus reaffirmed earlier this year that there should be a presumption against doing these tests in children," says Dr. Ellen Wright Clayton, a pediatrician and co-founder of the Center for Biomedical Ethics and Society at Vanderbilt University. But, she notes, it's an "uneasy consensus."

(**MORE**: Do All Women Need Genetic Testing Before Pregnancy?)

"There's no medical benefit to doing this in childhood," says Clayton. "Parents are supposed to shape their child's future — that's their job — but testing forecloses choice in a setting where we know that when given a choice, lots of adults forego getting tested."

As genomic tests grow increasingly sophisticated, parents could potentially find themselves faced with the prospect of being blind-sided by genetic results they hadn't anticipated. Say a sick child has her genome sequenced and test results reveal both the cause of her illness and the unexpected knowledge that she has an unrelated genetic mutation that puts her at increased risk of other diseases. "If you're looking in the area of chromosome 17 and BRCA1 is nearby, you can't ignore it," says Barbara Bowles Biesecker, director of the genetic-counseling program at the National Human Genome Research Institute, told TIME last year in a series of articles about the implications of sequencing children's genomes. "What are you going to do, put blinders on and not look to the left?"

(**MORE**: 'Both My Sons Deserve to Live': A Mother's Plea for Quicker Action from the FDA)

Yet even some women who have beaten breast cancer have decided that knowing about their own children's risk is probably not a good idea. Breast-cancer survivor Debbie Horwitz, a Raleigh, N.C., mother of two young kids, learned a few years ago that she inherited a breast-cancer mutation from her mother, who died of the disease. She was set on testing Jordan, her then-newborn daughter, but bowed to her husband's insistence that it made little sense. "I don't think it's fair for us to have that information now and have that heaviness in our family or in how we relate to Jordan," Horwitz said in the series. "I think knowing whether Jordan is positive or negative would also cause a lot of tension and sadness in our family."

Jolie didn't delve into her thoughts or worries about passing on a legacy of breast cancer. But it's a good bet that she will be wrestling with the same difficult decisions about whether — and when — to broach the topic of testing her children for BRCA mutations. Knowing our genetic history is becoming an increasingly important part of conversations we have with our doctors about our health. And that dialogue will inevitably influence the decisions we make about how we choose to treat disease.

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Bonnie Rochman writes about pregnancy, fertility, parenting — the ups and downs of being a kid and having one — for TIME.