

### Testimony of Rebecca Fisher

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We'll hear next from Rebecca Fisher.

MS. FISHER: I don't think I have anything to add to that. It seems almost like preaching to the choir, but I would like to thank the committee for everything the committee members have done in the past to address genetic discrimination concerns, and I hope that our remarks will help to inform your actions going forward.

In a provocative October editorial in the journal *Science* last year, Nobel laureate Sidney Brenner wonders what medicine will be like in the year 2053. "Perhaps," he wrote, "the prime value of our work to society will be the creation of a new public health paradigm in which those who have a genetic predisposition to disease will learn how to take extra care." Dr. Brenner needn't wait 50 more years to see this prediction realized. Some of us, those who possess BRCA1 or 2 mutations, known to predispose us to breast and ovarian cancer, are already taking extra care.

A recent study established that 67 percent of women with this mutation are diagnosed with breast cancer by the time they're 50 years old. But I have a cousin who died of it when she was 28. I have another who is battling Stage 4 ovarian cancer as we sit here today. She has a 4-year-old. My mother had breast cancer at 35. Her mother died of ovarian cancer at 41. Her sister had breast cancer at 32. I was 31 when I was diagnosed with Stage 3 breast cancer. My daughter, a 21-year-old, is in this line, too. She tested positive for BRCA1. She will also have to learn how to take extra care.

But the care that Katie will have to learn how to take includes not only the low-fat diet she's already eating and the daily exercise regimen she's undertaken. It includes more than the breast self-exam she's required to perform monthly, and believe me, I do remind her. It even goes beyond the MRIs of her breasts she will start receiving when she turns 25. The extra care she will have to learn how to take demands that she, like me and like everyone in our family who has this mutation, hide -- that is, hide, H-I-D-E -- her genetic information even, and perhaps especially, from those health care providers most likely to help her manage her lifelong predisposition to disease.

Unfortunately, that's what we're reduced to. Hiding integral health information is the only fail safe way we can avoid discriminatory practices such as the loss or denial of health insurance or the loss or denial of employment, because there simply is no comprehensive federal legislation that patently forbids insurance or employment discrimination on the basis of genetic information.

The argument has been advanced most recently and very publicly in the *Wall Street Journal* last March that seeking to ban DNA discrimination isn't really necessary because discrimination simply doesn't exist. Actually, it does exist, but the fact that it exists only sporadically and anecdotally is a function of the newness of the technology and the fact that useful predictive genetic information like ours is not yet ubiquitous. It is not a function of insurance companies' and employers' decisions to take the moral high road and, out of the kindness of their hearts, remain disinterested in this information in the same way that they are legally obliged to remain disinterested in information such as race, gender, creed, or sexual preference.

I know from experience that insurance companies don't work this way. When I was sick, I worked as a medical librarian for a small community hospital in south Florida. The hospital was self-insured. Pay attention to this part. The hospital was self-insured, and a third-party administrator managed our insurance plan. About a year after my last treatment, I was sitting at

my desk when the phone rang. The flustered young woman at the other end of the line told me I was the fourth person she had been transferred to, and someone along the line had suggested to her that perhaps I could give her the information she needed.

Perhaps I can, I offered. Well, she began, I am calling about Rebecca Fisher. Her bone marrow transplant and other health care costs exceeded the calendar year cap last year, and I'm calling to find out if that's going to happen again this year. I'm Rebecca Fisher, I said, and I really hope not.

This experience taught me something. It taught me that there are people who are paid to look at me and see not my ability to contribute to a community, not my honesty, my integrity and my faith, not my education, hard work, and social conscience, not my family members and the ways in which I have helped each of them succeed, but dollar signs, costs, increased liability, and the odds of my dying an expensive death.

Let us face the fact that financial incentives to use genetic information are already present. The Washington Post reported just last month that employer-sponsored health insurance premiums rose 11.2 percent this year and are expected to rise 13 percent next year. With these increases in mind and no enjoiner against using genetic information to predict future losses, it is a failure of stewardship, and I feel terrible that this committee has done this repeatedly, sent letters to Secretary Thompson repeatedly without any action. It is a failure of stewardship to expect companies and employers to simply do the right thing, and when they don't lavish precious man hours, health care hours, and litigation costs to undo the damage.

I fear for my children, especially for my daughter, who must live not only with an exponentially higher risk of developing a terminal disease but also with the burden of never knowing whether or when she will legally be asked to take a genetic test as a condition of employment, be lawfully fired from a job because she's very likely to get breast cancer, or be legitimately denied health insurance or life insurance on the basis of her genetic predisposition to disease.

We live in a world that has no safety net for us, not even HIPAA. Many people simply do not understand that HIPAA is no panacea for all that ails health privacy. The HIPAA gap means that HIPAA addresses none of our workplace concerns, and ERISA rules exempt, exempt, employer-based health plans like the one at the small hospital where I worked from mandatory HIPAA compliance. If my BRCA1 positivity had been known in 1994 and the HIPAA protections of today were in place then, the young woman on the other end of the phone could well and legally have recommended to her superiors, and probably gotten a bonus for doing it, that I not be extended further health insurance coverage.

The HIPAA gap is deep and wide. Of the 137 million private sector American employees who have health insurance, a whopping 45 percent -- this is from Steve Donohue at the Department of Labor -- a whopping 45 percent, that is 63 million Americans, fall into it. The genetic information of each one of these individuals, together with the information of every uninsured American -- that's another 45 million people -- is fair game.

In my opinion, genetic information is no different from any other essential distinguishing information about any human being, all of which is by law kept off the bargaining table that bears up this human rights-based society. But if this argument is truly different -- okay, I'll give you this. If this argument is truly different, if because of its fiscal component, as the United States Chamber of Commerce might argue, we must locate this debate within the framework of an implicit utilitarianism, I would point to professional contributions I and other genetically vulnerable people have been able to make because we've been lucky enough to remain considered

employable.

I would point to the contributions my daughter, 21 years old, hopes to make with her two degrees in public policy and economics from Duke University. I would point to the way in which our family's completion of innumerable psychological questionnaires, the donation of tissue from our bodies, and the giving of our blood have advanced medical science. I would argue that we are, in fact, making a difference for the health of all people, everyone in this room, that we've lived up to our end of the social contract and deserve the same fundamental legal protections that are extended to all Americans.

Last summer, attorney Lawrence Lorber, representing the U.S. Chamber of Commerce, the loudest voice speaking against federal genetic information protections, told the House Education and Workforce Committee that the possibility of employers being accused of engaging in genetic discrimination would be disastrous for them from both a legal and public relations perspective. He offered this as proof that genetic discrimination legislation is unnecessary.

I would like Mr. Lorber to tell that to my friend Susan, a 38-year-old woman whose sister is being treated for breast cancer, whose mother had pre-menopausal breast cancer, and aunt who died of it. We sat together at one of our son's ice hockey games last winter and she shared her story. Without wanting to push, I gently asked her whether she had considered speaking with a genetic counselor. Oh no, she exclaimed, I would never want to risk losing my insurance. This woman is a master's prepared therapist who watches CNN and reads the paper.

Fear and innuendo surround the brave new world of genetic information. People are afraid. Their fear keeps them from being tested, even when this test might make the difference between whether they live or die. And at the risk of sounding paranoid, I would go on to suggest that none of us present today can afford the luxury of writing off this problem to high-risk individuals like me. The stage is already set for a problem of catastrophic proportions. Guthrie spot programs whereby every newborn infant's blood is collected, screened and stored are found in all the states and territories of the U.S. and provide what is potentially the largest and most complete genetic bank and library available in the country.

The continued non-use of genetic information implied by insurance companies' and employers' lack of interest to date does not provide safeguards for any of us, high-risk or not.

MS. MASNY: We'd ask you in one minute to wrap up, please.

MS. FISHER: I'm almost done.

We with strong family histories of disease in which the baton of illness has been passed from generation to generation are simply the first line of defense against a staggering spectrum of possible abuses. We want to be heard, we want to be protected, and we don't want to sit in the back of the bus anymore. Thank you.

MS. MASNY: Thank you very much. I disagree with your opening statement that you didn't have anything more to add, because you definitely had a lot more to add. Thank you for your very powerful testimony.