## Testimony of Paula Funk

Now we'll hear from Paula Funk.

MS. FUNK: Good morning. Thank you so much for inviting me to come and talk about my story. When you're going through the process of finding out your genetic predisposition, sometimes you feel alone. Last night I was thinking this isn't anything I should be nervous about because you're here to help me, and I really appreciate that invitation.

My name is Paula Funk. I'm a mother of twin 3-year-old daughters, and I have a husband that's here with me to support me today. My family has a strong history of breast and ovarian cancer. I'm going to tell you a little bit about my family.

My dad is one of ten children, and he has five sisters. All five of his sisters have had breast cancer, and the current count right now is that eight of my cousins have had breast cancer as well. The number breakdown there, that is 13 women out of 24 that have had breast cancer. This disease is something that the women of my family have to constantly think about. There's a constant threat.

My first memory in life is taking my aunt Dorothy to her weekly treatments to fight breast cancer. It's a sketchy memory, but I remember clearly a sweet lady lying down in the back of my mom's station wagon in a pink nightgown. We took her to treatment every week, and that was the beginning of my understanding of what my future had for me.

My sweet aunt Dorothy has survived breast cancer twice and is now fighting an aggressive form of ovarian. This month she's going to have to have a surgery to repair tissue that all of the treatments for cancer have torn a hole in her chest area, and they're going to have to do treatment just to patch that area. This makes me really sad. It makes me feel like I have to aggressively fight my possibility of cancer.

Ten years ago I started realizing this, and I decided to pursue genetic testing. At that time, genetic testing required several women from one family to give a blood sample to determine if there was in fact a genetic mutation. I approached my aunts and my cousins about this, and they talked to their physicians, and their physicians recommended that they not pursue genetic testing because at the time people could deny insurance and the discrimination could be even worse in the future as more was learned about being genetically positive.

Because of this, I chose not to have the test at the time. I was 23, and 30 seemed like a long way away. Well, I'm 33 now, and I'm in the middle of where most of the women in my family begin to get breast cancer. Two of the women were 30 when they were diagnosed. Because I am in the middle of that stage where most of the women get breast cancer, in May of 2003 I decided to consider being genetically tested again. I talked with a genetic counselor, and she asked me a lot of questions about insurance. It was an unfortunate time for me to want to pursue it. My husband and I had just opened our own small business. We were the two people in the business.

As I researched about individual insurance, I learned that even with the gaps that HIPAA provides, it's a biggest protection than what individual insurance provides. There's no protection. It's considered free market, and they can deny you for anything. As a matter of fact, I was denied from individual insurance because I had had a C-section.

Because of this, we began looking to see if we could find a group insurance policy for two people. Almost all of the insurance companies required three to five people to qualify as a small group. I finally talked to UnitedHealthcare, which allowed a two-person company to be considered a group. If they had not accepted this, my husband and I were going to have to close our small business, and he was going to go to work for a large company so we could have protection in a large group.

I'm thankful that they accepted me as a small group, but I live with the fear every day that I could be rejected.

During the time that I was trying to find insurance, I asked my father if he would be tested first because the genetic disorder was going through his side of the family, not my mother's, which is what we usually hear. He took the genetic test and came back positive. I knew from my research that I had a 50/50 chance of carrying this mutation as well. It was tortuous waiting the three months to find out if I could have insurance, but I finally was able to take the test, and I took came back BRCA Strain 1 positive. This means that my twin daughters have a 50 percent chance of having the mutation as well, and I have up to an 88 percent risk of breast cancer in my lifetime, and up to a 44 percent risk of ovarian cancer as well.

Ovarian cancer is particularly alarming to me because I've heard that there's a 50 percent mortality rate once you are able to be diagnosed with it.

I'm so grateful that I have an opportunity to save my own life, though. I hope to have a prophylactic mastectomy this fall, and I've been told that it gives me a 95 percent chance that I will never have breast cancer. After I'm finished having children, I plan on having my ovaries removed as well. That too will give me a 95 percent chance that I will never have ovarian cancer.

There was a point where the fear of death just outweighed my fear of discrimination. That's why I pushed through with being genetically tested in spite of my fears. I have had several problems along the way because I was tested genetically. The first one I mentioned earlier. We put off being tested for 10 years because of what the physicians recommended because of the potential discrimination. Countless women in my family during the last 10 years have been diagnosed with breast cancer, and several of them have lost their battle to breast cancer. That could have all been prevented if we had pursued testing then.

That really grieves me thinking about the loss of life there that could have been avoided. I've decided that knowledge about my health is a gift. I want everyone to feel the freedom to have that gift. My dad and I paid for our own tests because of our fear, and then my doctors, after I was diagnosed with BRCA Strain 1 positive, changed my diagnosis code for each procedure they requested. When I had my breast MRI, they didn't write that I'm BRCA Strain 1 positive. They didn't feel safe for the protection of me. They simply wrote that I had a strong family history, and I know that that means that there is discrimination out there or they wouldn't do that. Being BRCA Strain 1 positive is a stronger case than having a strong family history.

I am in the process of sending out information packets to 86 different addresses of my direct relatives and thinking about the fact if there are 86 different addresses, how many different people live there, because this is a disease that affects men and women. Men have the same chance of carrying this strand as women do. As I talk to my family members, the amazing thing to me is they have more questions about genetic discrimination than they do about how it affects their health. That is so sad to me, and most of the relatives that I've talked to have refused to take the test because of that fear. I can't help but think that just in my family, if we could all band together, how much we could do for the research of genetics if they felt the freedom to be tested.

I have one cousin that desperately wants to take the test, but her husband is a preacher at a small church and they have an individual insurance policy. So she can't take the test. There is no protection at all for her. She's 35. She's two years older than me. Of the 13 women in my family that have had breast cancer, most of them have been in their 30s. It makes me so sad that she has to wait until she has cancer until insurance will pay for a procedure.

One last area of concern is a problem that I'm having with insurance currently. I have had my insurance for less than a year. Other than the basic screening tests that I've had to determine whether I currently have cancer or not, such as CA125 counts, ultrasounds, mammograms, a breast MRI and a needle biopsy, there have been no other expenses this year, and I was just informed that my health insurance has been raised $100 a month with no explainable reason. I've talked to several medical people and they say that this is unusual and looks suspicious.

Another problem that I'm having currently is that prophylactic measures are not something that they automatically cover. Over two months ago I requested for them to agree to cover a prophylactic mastectomy for me. It has been over two months and no progress has been made on this issue. My father had bypass surgery five years ago, and there was no board of review that he had to go to for that surgery, and I don't understand why I have to sit and wait during that two months.

One thing that I would like to leave you with is I so appreciate you listening. My medical management and the medical management of many in my family have greatly been affected both by genetic discrimination and just the fear and the possibility of it. Unwitting discrimination has become a major part of my daily life. Discrimination worries me so much for the future as well.

Last Saturday my husband Jonathan and my two daughters, Audrey and Anna, and I walked in the Race for the Cure. My 4-year-old daughters had so many questions about what was going on and what was it about, and my answers had to be simple because they were so young. But I couldn't help but think what a complex issue this has been for me. My prayer is that when they are old enough to decide whether they should be tested genetically, that discrimination isn't even part of their decision process.

Finding out your genetic status is permanent. You can't take it back, and it isn't something that you can change your mind on. What I really need, and what we all need, is a law that clearly defines the safety and the fact that you cannot be discriminated against genetically. We don't know what the future holds or how society is changed, so at this point I'm very vulnerable depending on the direction that that goes.

Thank you so much for your time, and thank you for inviting me to tell my story.

MS. MASNY: Thank you, Ms. Funk.