

### Testimony of Phaedra Malatek

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Now we'll hear from Phaedra Malatek.

MS. MALATEK: Good morning, Chairman Tuckson and members of the committee. Thank you for giving me the opportunity to speak with you today. My name is Phaedra Malatek. I am a wife, mother, sister, daughter, and friend of people who care very deeply about what we're doing here today.

I live in Aurora, Illinois with my husband and two sons. My primary occupation is adjunct faculty at two local community colleges. Otherwise, I'm involved nationally and locally on issues related to women's cancer. But I'm here today to talk to you about the hope that lies in genetic testing, more specifically the Genetic Information Nondiscrimination Act, S. 1053. I talk about hope because, as Ralph Waldo Emerson says, "We judge of a man's wisdom by his hope," and today I'm feeling pretty wise.

For me, genetic testing and the protection offered by S. 1053 can be compared in an analogy to weather tracking or storm prediction. Imagine, if you will, that we had no knowledge of the storms that recently swept through the southeastern United States and the Caribbean. How would the death toll change? How would the damage assessment change? How would the insurance industry have changed? Now imagine never having any information about any storm ever. Well, I think our understanding and consideration of genetic testing can be compared to those "what ifs."

What if people were given the knowledge of the potential storms in their lives? How would they be able to protect themselves? What would serve as the plywood for the windows, and what evacuation routes would be made available to them? More importantly, how many lives would be saved? Because that really is the question, isn't it? How many lives can we save by what we're doing here and through the enactment of S. 1053?

Continuing the storm analogy and the concept of discrimination, let's consider a situation where you know that a storm is coming, or that may come, and you take the precautions such as boarding up your windows and putting the lawn furniture in the pool, but you're unable to get insurance simply because you know a storm may come? Your neighbor, on the other hand, has no knowledge of the storm and doesn't take the necessary precautions. If the storm doesn't hit, that's all fine and good. Everybody wins. However, if the storm does hit, the insurance company provides full financial reimbursement for your neighbor's severely damaged or lost property, but there's no coverage for your property no matter how small or large the loss.

It seems to me that that's what we're talking about with genetic discrimination, a situation in which no one wins and everyone loses. Those with advance warning are actually harmed rather than helped by the knowledge they possess. Insurance companies and those without advance knowledge even larger losses because they have been given the knowledge to protect themselves. If fair warning is given to all parties through genetic testing, the people who are able to protect themselves and the insurance companies who agree to be at risk for any loss suffered all have a much larger measure of protection.

Those who are informed about their risk can be proactive and take either prophylactic measures or be monitored more closely, increasing their ability to entirely avoid developing a disease or having it detected in its earliest, most treatable and survivable stages. As we all know, this not only saves lives but dramatically decreases the cost to employers, insurers, and the individual.

A storm such as this hit my life a number of years ago. In 1991, my father gathered together his children, siblings, nieces, nephews, cousins, to discuss a disease that he had been diagnosed with. The disease is hemochromatosis, which is often referred to as iron overload. My father had been exhibiting symptoms prior to diagnosis, including arthritis, heart arrhythmia, and a change in skin tone. At the time he was diagnosed, his heart and liver were fully involved. At the same time, his physicians conjectured that my grandfather and great-grandfather may have also carried and suffered the effects of this disease.

Within a year of our meeting, my father suffered a heart attack and within 10 years had died from the disease. Since my father's diagnosis, two of my siblings have developed complications of the disease. None of them, my father or my siblings, have had genetic tests for hemochromatosis. Because of my family's history with hemochromatosis and the fact that it is the most common inherited disease in the United States, my husband and I are concerned for the welfare of our two children.

Mitchel and Trevor, who are here with me today, throughout their lives we received conflicting information on how to approach their risk for hemochromatosis. We were told to have periodic blood tests to measure their iron level. We were told to do nothing. We were told to constantly monitor their diet. While all of this may have been good advice, none of it replaces knowing for certain that Mitchel or Trevor carried the genetic mutation for the disease that contributed to my father's death and is an issue in the life of my siblings. With that knowledge, we could have taken proven knowledge to lessen the impact the predisposition for this disease might have on their lives.

Like storm predicting and tracking capabilities, genetic testing seems to offer an opportunity to learn more about the constitution of diseases and their potential serious damage. It can help us track the progression of a disease, as well as determine treatment or even protective measures to avoid the storm that may result from a genetic mutation. For my children, this could be life-altering information, altering in that it will decrease the likelihood that they will be incapacitated by hemochromatosis.

For diseases such as ovarian cancer, it can mean the difference between prophylactic treatment that could allow women at high risk to lead long, successful lives, and the stark contrast of the often futile and very painful death-prolonging treatment.

Throughout the recorded history of hurricanes, experience has gone from storms that came out of nowhere as recently as 100 years ago to those that we were able to track minute by minute 100 days ago. The dramatic change is not a result of the decrease in the power of the storm but rather an increase in technology and our understanding of hurricanes. Along the same lines, technology and advances in the area of genetic testing can similarly provide predictability and a greater level of protection for those at risk, and that risk, or even the knowledge of the potential risk, can be protected through S. 1053. While the technology for physical protection through genetic testing seems to be in place, or at least advancing at a relatively rapid clip, the social and economic protections are not.

As it stands right now, if my children undergo genetic testing for hemochromatosis, they risk not being able to obtain health insurance when they're no longer covered under my husband's policy and possible discrimination when they seek employment. So we're given a choice: protect their health or protect their livelihood. It's troubling to me that as Americans we're placed in a position where we have to make such a terrible choice. It also troubles me that S. 1053 offers protection

that would eliminate the need for my husband and I to decide such a difficult thing, and it's not been brought to a vote in the House of Representatives.

All of this is reminiscent of a series of choices that were being made 40 years ago. In the late '50s and early '60s, my parents fought diligently for the rights of people who were genetically different from them. They were not different in that they were at higher risk for obtaining hemochromatosis or ovarian cancer but that their skin was a different shade of beautiful. My parents, along with many others, won that fight. The Civil Rights Act amendments are there to protect people from discrimination based on genetic makeup that we can see, be it skin tone, gender, or disability. A person's genetic makeup that isn't visible should be equally protected under the same terms and can be through S. 1053.

It's remarkable for me to realize that the work my parents did for the Civil Rights Act in the '60s was not complete. Here I am, 40 years later, working on the same issue, equal rights and protection under the law no matter the genetic makeup of a person. The fact that we can look inside the DNA of a person to know more about them should not preclude them from the protection that was fought for so valiantly. As I see it, genetic testing is the weather tracking device of health. Just as we rely on weather tracking technologies to predict and to allow us to protect ourselves from hurricanes or other weather-related storms, I urge you to allow us to do the same for genetic diseases.

We must move forward in protecting people from the potential storms in their lives. You can do this by urging Secretary Thompson and my representative, Speaker Hastert, to bring this bill to a vote in the House of Representatives. I'm sure you can agree with me when I say that protecting lives is equally or more important than protecting property. If we can, we should, and S. 1053 will.

MS. MASNY: Thank you, Ms. Malatek. That was such a beautiful analogy between the genetics and storms.