Testimony of Phil Hardt

Lastly, we'll hear from Phil Hardt.

MR. HARDT: Good morning. It's a privilege to be here today, and I want to thank the committee for inviting me to share my thoughts and personal experiences with everyone on the critical subject of genetic discrimination.

I have two genetic diseases, hemophilia B, a bleeding disorder, which I inherited from my mother, and also Huntington's disease, a degenerative brain disorder, which I inherited from my father. My two biological daughters and granddaughters are all carriers of hemophilia B, and as a result I now have two handsome grandsons who must also infuse with clotting factor each time they get hurt. All three of my biological children were at risk for Huntington's disease, but I am happy to report that none of them carry the destructive gene and cannot pass it on to subsequent generations. One tested publicly, and two tested anonymously to conceal their outcomes.

I mention biological children because I also have five adopted children, four of whom have severe handicaps.

Nevertheless, our story is one of continuing genetic discrimination even though we have laws that are supposed to protect me, my children, and my grandchildren.

"It was the best of times, it was the worst of times," as Dickens said in "A Tale of Two Cities." Because of advancements with the Human Genome Project, we now stand on the brink of having more useful information that has the potential of helping literally millions of individuals prepare early for various diseases. However, the reality is the knowledge that you are carrying any particular genetic disorder, in my case hemophilia and HD, is just as devastating to you, your children and your grandchildren as the disease will be later. This is further exasperated in Huntington's disease because of the severity of its symptoms and the absolute necessity for those who face the 50/50 chance of inheriting it to prepare early and thoroughly in order to minimize its overall destruction.

Tens of thousands of individuals with Huntington's disease have lived and died and are already in the insurance company's profitability calculations. However, it wasn't noted on their death certificates because of genetic discrimination fears. It is ludicrous now to believe that because you can know early that you might inherit a genetic disorder that all of a sudden we're going to create higher medical costs. This is not the case. We are living examples of the Tiresias complex. If you remember, the blind seer Tiresias confronted Oedipus with the dilemma, "It is but sorrow to be wise when wisdom profits not."

Huntington's disease is an inherited progressively degenerative brain disorder that results in loss of both mental faculties and physical control. It causes brain cells to die prematurely. Loss of these brain cells causes very specific impairment and eventually death. Every child of an affected parent has a 50 percent chance of inheriting the gene and developing the disorder themselves. If HD is passed on by the father, another risk exists of anticipation occurring and each gene-positive child becoming symptomatic, even as early as a young infant or in their teenage years.

HD symptoms debilitate a person when they least expect it, usually in the prime of their lives, around 40 years of age, when they still have children at home and are actively pursuing careers. Living with HD is like living with Alzheimer's, Parkinson's, MS, and going insane all at the same time. Genetic testing has been available for Huntington's disease for longer than any other adult-

onset disorder, since 1993. The discovery of the genetic mutation causing Huntington's disease made possible the use of predictive testing to identify current unaffected carriers. In 2000 Cohen said, "Genetic testing is intended to give families with a family history of HD the opportunity to assess their own risk for developing the disease more specifically, monitor their health status closely and, if a predictive mutation is present, make informed choices about reproduction and lifestyle."

It is interesting to note here that before 1993, the almost quarter of a million individuals who are at risk for HD in the United States were polled, and overwhelmingly about 90 percent of them said that they would take advantage of the test to find out if they were carrying the destructive HD gene. However, since the definitive test became available, fewer than 10 percent have tested as a direct result of genetic discrimination.

I'd like to now tell a little bit about my family history. In 1971, I was diagnosed with hemophilia B. In 1989, I was hired by Allied Signal Automotive and told by the HR manager there not to tell my boss about my hemophilia or I would never be promoted or trained because he wanted to get the biggest return on investment for his bucks, and if he knew I might have a disability, I would never go anywhere in the company. Consequently, all future bleeding episodes had to be hidden from him.

In 1996, a claim I filed for credit insurance on a car I had purchased for my daughter was denied because I had recently seen a neurologist regarding problems that I was having. In 1997, I was diagnosed as having Huntington's disease. In the year 2000, my oldest daughter married and applied for mortgage life insurance. She was turned down by every major insurance company because of Huntington's disease. Copies of several rejection letters are included in your packets, and note that the insurance companies don't even have fear of putting their rejections in writing.

Each of her rejection letters state two pertinent facts that are important. Number one, they each state that they will not insure her until she has tested for Huntington's disease, and two, that she is found to be negative. Then the insurance agent on one of the letters where they insure her husband writes a note at the bottom that says when you find out your status for HD, then we can insure your children, showing that the discrimination is down to the third generation now.

In 2002, my grandson, Enoch Maximillion, is denied health insurance coverage because of hemophilia that he inherited from me, and a copy of this denial is also included in your handouts. They must now earn less than they are capable of to qualify for state welfare in order to get coverage.

In 2002, my daughter Michelle and son Phillip tested anonymously for HD to protect them in case either of them tested positive. I am over the Huntington's Disease Society of America, Arizona affiliate in the State of Arizona, and in 2001 a geneticist and I established anonymous genetic testing to protect individuals so that they can use a bogus name and social security number and address and all other information, and pay cash. But the problem is it's very expensive. It's around $900 out of pocket to find out. But it is completely concealed. But it's a shame that we have to do this.

Last year I applied for long-term care insurance and was rejected on the basis of my HD after becoming divorced and realizing that I would probably need someone to take care of me later.

Now, here is a list of ways that open genetic discrimination adversely affects those with HD over and above the negative effects of the disease itself. Those who are at risk are reluctant to

participate in research, even anonymous research, because they fear being found out. For example, the PHAROS study for HD could have almost a quarter of a million at-risk individuals in it, but they have only been able to recruit about 1,000. Imagine the decrease in numbers. Other important research tests are no different. Because of our small numbers, unfortunately, we need every bit of data possible to make things significant.

Proper medical and mental health care are not sought on a timely basis that could have (inaudible) help reduce suffering and raise everyone's quality of life. Open communication is almost non-existent between parents and their at-risk children regarding how they can better prepare to minimize the destruction of HD if they do have it. HD must be kept shrouded in secrecy to protect everyone. For the same reason, at-risk children are not encouraged to seek good education, college education, careers with companies who offer group benefits, marriage and childbearing options, including adoption. Misdiagnosis and the same thing with medication occur because one doesn't know, or knows but can't be honest with their doctors and other health care providers for fear of being discovered. Healthy living habits aren't adopted either early on to postpone onset.

Now, using our negative experiences with being wise and our wisdom not only doesn't profit us but is even used against us. How many other future discoveries that have the potential to bless the lives of millions of others by predicting other diseases soon enough for individuals to take positive action against them will be thwarted because of flagrant genetic discrimination?

Thank you very much.

MS. MASNY: Thank you, Mr. Hardt.

And thank all of you for your very profound testimony.