Testimony of
Sharon F. Terry
President and CEO, Genetic Alliance
Chair, Coalition for Genetic Fairness

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Subcommittee on Health
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Chairman Pallone, Representative Deal, and Members of the Subcommittee, thank you for bringing us to this moment and for the opportunity to testify here. Representatives Slaughter, Biggert, Eshoo and Walden demonstrate robust vision and courage to introduce again the legislation that will make it possible for Americans to benefit from new genetic tests and technologies.

My name is Sharon Terry and I represent millions of Americans affected by genetic conditions.

I am president and CEO of Genetic Alliance, a coalition of more than 600 disease support groups, and I am chair of the Coalition for Genetic Fairness. Mine is not a chosen profession, it is a vocation thrust upon me when my children were diagnosed with a genetic condition that will rob them of their vision in the prime of their life. Quite poignantly, the Genetic Information Nondiscrimination Act of 2007 will not protect my children, or the millions I officially represent. They all have manifested disease, and this bill, appropriately, does not protect them. This is a critical point often obscured in many of the arguments against the legislation. This bill is not about those who already have signs or symptoms of disease, but rather about those who carry a genetic mutation, which increases their chances to develop a disease or condition. This is a critical point often obscured in many of the arguments against the legislation.

Though I do not personally benefit, I have worked on this legislation for 12 years, since Chairwoman Slaughter first introduced it. With others present here, I founded the Coalition for Genetic Fairness to support this legislation – and we have had a long and uphill battle. We are several hundred organizations strong and include members from every sector of society – disease support groups like Facing Our Risk of Cancer Empowered; healthcare professional organizations like the American Society of Human Genetics, National Society of Genetic Counselors, and American Academy of Pediatrics; women's leadership groups like Hadassah, The Women's Zionist Organization of America, labor groups such as the National Workrights Institute, academia like Brown University; and most significantly, companies like Affymetrix, IBM, and 20th Century Fox. We thank them and those of you, who year after year, supported this legislation and are impatient to see it pass. We have compromised and conceded a great deal during these years, and we believe that the bill before you is fair and well balanced.

The faces and the voices of the hundreds of individuals who have contacted us, fearing for their children, their families, their jobs, their insurance, have fueled my passion for more than a decade. Men, women, and children – families from communities all across this country – have told us their stories and in some cases, pleaded for us to help them.

In 2003, Heidi Williams of Kentucky called me when her children were denied individual health insurance from Humana, Inc. Heidi has alpha-1 antitrypsin deficiency, an autosomal recessive genetic disease. Humana rejected the children's application stating that since the children were carriers of alpha-1 antitrypsin, Humana could not cover them. With our help, Heidi explained in an appeal that carriers of genetic conditions are not affected by the condition, but Humana again denied her children health insurance. I then called a reporter from a prominent national newspaper and told her Heidi's story. The reporter called Humana and Heidi received notice of retroactive coverage late that same night. This year, Heidi's daughter Jayme Williams wrote this letter to her congressman:

> Dear Congressman Ron Lewis,
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> My name is Jayme Williams, and I am in the fifth grade and live in Cecilia, Kentucky. My brother and I are carriers of Alpha-1 Antitrypsin Deficiency, a defective gene in our DNA that can be passed on to our future children. While my brother and I both have only one defective gene, my mother was given two, one by her mother and one by her father. The two genes make my mother's lungs very sick. My brother and I were denied health insurance because we carry mutations in the Alpha-1 gene.
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> My mom tells our story because other people are too afraid to tell theirs. Discrimination makes people very afraid. When people are discriminated against, they are sometimes told they will lose something they need if they speak out against the people causing the discrimination.
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> I think you should support the bill that is before the House of Representatives that would make it illegal for anyone to do this to another person in the USA. My mom says that everyone is created equal, and deserves to be treated fairly. Please help my mom stop people from treating others unfairly.
>
> Sincerely,
> Jayme Williams

Let resonate these heart-felt words from a young girl who cannot imagine that carrying a mutation in a gene makes her uninsurable. I assured her that we would continue to work hard so that she and others like her are not discriminated against again.

I am also reminded of Becky Fisher, who shares a mutation for inherited breast cancer with many in her family. Having watched her mother, aunts, and cousins die of breast cancer, and she herself surviving cancer, she thinks only of her daughter, who was brave enough to be tested, and says of her:

> One of the not-so-good things is that having a documented genetic mutation makes her vulnerable to more than just a devastating illness: she also faces the heavy 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 of the high cost of her potential medical care, or be legitimately denied health insurance on the basis of her genetic predisposition to disease.

We are all Heidi and Becky's children; we all carry mutations for dozens of diseases, and we are all vulnerable. Aren't health and disease enough to worry about? We cannot afford to also worry about discrimination based on these mutations, silent mutations, with no signs or symptoms. This is simply about preventing the misuse of genetic information, that which makes up every one of us, our shared inheritance, and that which makes each of us unique.

This also about special interests: let us put the special interest of the health of all Americans above all else. Every one of you, and each of your loved ones, is at risk for some disease or another. We cannot yet easily reduce that risk, but it is in your hands to reduce the risk of discrimination associated with that information. At the end of the day, we are relying on you to make it possible for individuals to use their genetic information for the health purposes for which it was elucidated. Some might say that Dr. Collins and his colleagues have done the hardest work, but we understand that balancing the policy needs of a nation is also difficult – you are pulled and pushed in many directions. . Please measure your decisions against 'what truly matters' when voting in committee and the full House floor in the next weeks. Please remember that none of us have any choice over our ancestry, our different abilities, or our genetic makeup. As a nation we do have a choice about how we treat that information.

Every American is affected by this legislation. Beyond health insurance companies', trade associations', and employers' needs, all those who carry genetic mutations they did not choose are asking us to take necessary measures to alleviate the burden discrimination — and the fear of discrimination — places on our nation. I have faith and hope that you will chose to relieve their burdens, my burden, your burden. I look forward to the good work you will do over the coming weeks. Thank you.

Biography

Sharon is President and CEO of the Genetic Alliance, a coalition of over 600 disease specific advocacy organizations working to increase capacity in advocacy organizations and to leverage the voices of the millions of individuals and families affected by genetic conditions. She is the founding Executive Director of PXE International, a research advocacy organization for the genetic condition pseudoxanthoma elasticum (PXE). Following the diagnosis of their two children with pseudoxanthoma elasticum (PXE) in 1994, Sharon, a former college chaplain, and her husband, Patrick, founded and built a dynamic organization that fosters ethical research and policies and provides support and information to members and the public.

She is at the forefront of consumer participation in genetics research, services and policy and serves as a member of many of the major governmental advisory committees on medical research, including the Food and Drug Administration Cellular, Tissue and Gene Therapies Advisory Committee and the Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children. She served as an Ethical Legal and Social Implications Research Advisor of NHGRI/NIH, the National Institute of Arthritis Musculoskeletal and Skin Diseases Council and currently is liaison to the National Advisory Council for Human Genome Research. She is a member of the board of directors of the Biotechnology Institute and on the advisory board of the Johns Hopkins Genetics and Public Policy Center funded by the Pew Charitable Trusts. She serves on the boards of the Coalition for 21st Century Medicine, the Personalized Medicine Coalition, DNA Direct, and the Center for Information and Study on Clinical Research Participation. She is the chair of the Coalition for Genetic Fairness, composed of advocates, healthcare providers and industry working to enact effective federal policy to prohibit genetic information discrimination. She is also chair of the Social Issues Committee of American Society of Human Genetics. In 2005, she received an honorary doctorate from Iona College for her work in community engagement and haplotype mapping.

Ms. Terry is a co-founder of the Genetic Alliance Biobank and serves as president of its board. It is a centralized biological and data [consent/clinical/environmental] repository catalyzing translational genomic research on rare genetic diseases. The BioBank works in partnership with academic and industrial collaborators to develop novel diagnostics and therapeutics to better understand and treat these diseases. Along with the other co-inventors of the gene associated with PXE (ABCC6), she holds the patent for the invention. She co-directs a 19-lab research consortium and manages 52 offices worldwide for PXE International.

Sharon feels strongly that advocates, working together and partnering with professionals and industry, can generate the energy and mechanisms necessary to realize the promise of biomedical research. Her work with the Genetic Alliance over the past few years has particularly focused on genetic literacy, research protections, biosample repositories, technology translation, genetic nondiscrimination, accessible services and youth issues. She has published widely on these issues. Sharon is committed to facilitating technical assistance to advocacy organizations, so that each organization benefits from the wisdom of the other. Sharon lives with Patrick and their two children in Maryland.