

Testimony of Andrew J. Imparato
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Hearing On:

**Protecting Against Genetic Discrimination:
The Limits of Existing Laws**

Before the
Committee on Health, Education, Labor and Pensions
United States Senate
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Mr. Chairman and Members of the Senate Committee on Health, Education, Labor and Pensions:

Thank you for the opportunity to provide testimony regarding the important topic, “Protecting Against Genetic Discrimination: The Limits of Existing Laws.” I am honored to have this opportunity. My name is Andrew J. Imparato and I am the President and Chief Executive Officer of the American Association of People with Disabilities (AAPD), a national non-profit, non-partisan membership organization promoting political and economic empowerment for the more than 56 million children and adults with disabilities in the U.S.

The topic of today’s hearing is of particular interest to me, in part because I have a disability (bipolar disorder) that I believe has a strong genetic link. Assuming that scientists will some day (perhaps very soon) be able to identify the genetic marker for bipolar disorder, I am concerned that my two sons may experience discrimination if they are determined to have that gene. We need strong legislation that protects individuals with genetic predispositions so that my children and others are not subjected to discriminatory behaviors based on fears, myths and stereotypes of employers and others. I strongly encourage you to pass the Genetic Nondiscrimination in Health Insurance and Employment Act (S-318), so that my children and others will be protected by federal law against genetic discrimination in health insurance and employment when they have a genetic marker for a potentially disabling condition.

In 1993, I came to Washington, D.C. to join the staff of this Committee's Disability Policy Subcommittee when it was beginning the process of taking up national health care reform. It is a pleasure to be back as a witness. After leaving the subcommittee staff in November of 1994, I worked as an attorney adviser to Commissioner Paul Steven Miller at the U.S. Equal Employment Opportunity Commission, where I worked on Enforcement Guidance under the Americans with Disabilities Act (ADA). In 1997, I left EEOC to become general counsel and director of policy for the National Council on Disability (NCD), an independent agency advising the President and Congress on public policy issues affecting people with disabilities. While at NCD, I oversaw a study on federal enforcement of disability rights laws, including the ADA. I joined AAPD as its first full-time President and CEO in 1999. Founded on the fifth anniversary of the signing of the ADA, AAPD has a strong interest in fighting genetic discrimination both in health insurance and employment.

My testimony today will focus on the limits of the ADA in protecting against genetic discrimination, especially in the area of employment. The basic point of my testimony is that the ADA as drafted does provide some protections against genetic discrimination in employment, but the law has been interpreted by the Supreme Court and lower federal courts in a manner which weakens its protections. Whereas the ADA can be and has been used to stop genetic discrimination in some instances, the protections it affords offer little security to people with genetic markers and health conditions that have not yet developed into full-blown debilitating conditions.

In order to address today's topic, I will start with the definition of the term "disability" as used in the ADA. Anyone who does not meet the definition of that term falls outside the statute's protections.

The ADA defines a person with a disability as someone who meets at least one of three prongs in the definition:

- (1) a person with a physical or mental impairment that substantially limits at least one major life activity;
- (2) a person with a history of such an impairment; or
- (3) a person regarded by others as having such an impairment.

When Congress passed the ADA in 1990, Congress intended that the law would cover individuals with a broad range of diseases, such as epilepsy, diabetes, breast cancer, heart conditions and psychiatric disorders like mine. Indeed, some members of Congress even explained that the ADA would protect people who experience discrimination on the basis of predictive genetic information, on the grounds that such individuals would be "regarded" as disabled and hence covered under the law.¹

Unfortunately, in the years since the ADA went into effect in 1992, the ADA's scope of coverage has been significantly restricted. Particularly in the wake of a trio of Supreme Court decisions in 1999 that eliminated ADA coverage for many people with correctable impairments, individuals with conditions such as cancer, epilepsy, diabetes, heart and respiratory conditions, mental illness, and a range of other health conditions, who have

¹ See, e.g., 136 Cong. Rec. H4622 (daily ed. July 12, 1990) (statement of Rep. Owens); id. at H4625 (statement of Rep. Edwards); id. at H4627 (statement of Rep. Waxman).

experienced discrimination based on such conditions, have been turned away at the courtroom door on the grounds that they are not sufficiently “disabled” to receive legal protection under the ADA.² Regardless of how unfairly these disabled individuals may have been treated, they are being told they have no protection against discrimination under the ADA because they are functioning too well to be part of that law’s protected class.

In essence, the federal courts have required that to be covered under the ADA, an individual must be so debilitated by his or her impairment that it is difficult for the person to function at all. Moreover, if such an individual can take medication or receive a device (such as a pacemaker) that will enable the person to function, he or she will often not be considered “disabled” under the ADA. Also, even if an employer refuses to hire an individual expressly because of a health condition or genetic predisposition to develop a disabling health condition, this will not be sufficient to claim that the employer “regarded” the individual as disabled unless the individual can also prove that the employer believes many *other* employers would act the same way. The same reasoning that has eliminated legal protection under the ADA for individuals with a range of health conditions will likely be used to deny coverage under the ADA for individuals with predictive genetic information or family histories regarding such conditions.

² For a comprehensive discussion of how the ADA’s coverage has been significantly restricted, see Feldblum, “Definition of Disability Under Federal Anti-Discrimination Law: What Happened? Why? And What Can We Do About It?”, 21 Berkeley Journal of Labor and Employment Law 91 (2000).

It is critically important that we act quickly to provide strong anti-discrimination protection to individuals with genetic predispositions to develop potentially disabling conditions. The Human Genome Project and other advancements in genetic technology will present unprecedented risk for people with the genetic markers for a wide variety of illnesses. Fearing high insurance costs, absenteeism, and low productivity, employers may discriminate against people with predictive genetic information and family histories by firing or refusing to hire them, even though the employers' fears may be mere speculation. Equally troubling, the fear of possible genetic discrimination may prevent these men and women from seeking early diagnosis and treatment of their conditions.

Although I will outline below the possible ways in which the ADA could be used to protect individuals from genetic discrimination in the workplace, I am not optimistic.³ As it stands now, it would be very difficult for an individual with a genetic predisposition to disease to be covered under the law, just as it has proven difficult for individuals with the underlying conditions themselves to be covered. Clarifying legislation like S-318 is therefore needed.

There are two possible ways the ADA could be used to cover individuals with genetic predispositions to disease. First, possessing such a genetic marker could be seen as substantially limiting the major life activity of reproduction. In 1998, the Supreme Court held in *Bragdon v. Abbott* that reproduction was a major life activity and that asymptomatic HIV infection created a substantial limitation on that activity. The fear of

³ The following testimony draws on a letter from Professor Chai Feldblum of Georgetown University Law Center to Senator Tom Harkin, dated July 18, 2000.

passing a genetic disease on to one's offspring, like transmitting the virus that causes AIDS, could be found to substantially limit reproductive decisionmaking.

There are several problems with this analysis, however. The definition of disability under the ADA clearly requires that the condition be a physical or mental impairment. It is not clear that a court would find an individual's genetic make-up to be an "impairment," particularly since genetic predispositions often have little or no present effects on the individual. Furthermore, even if having a genetic predisposition was found to be an impairment, it may not be found to substantially limit the major life activity of reproduction if there is only a small probability of the individual passing on the disease.

Central to the Court's reasoning in *Bragdon* was the quantified risk of a woman with HIV infection passing the disease to her offspring. The Court cited studies placing this risk as high as 40 percent. Using this logic with a wide variety of genetic predispositions would thus hang protection on the degree of *risk* of transmitting the condition. Some genetic markers (e.g. for Huntington's disease) that present more serious risks of transmission might be covered, while others (e.g. for breast cancer) might not. The illogical result would be that an individual's protection from discrimination on the basis of a genetic marker would *depend* on how likely it would be that the marker would affect the individual's procreation decisions.

Finally, if this analysis prevails for genetic markers, it presents the possibility of having the genetic predisposition for one of these diseases covered by the ADA, but, ironically

and unfortunately, not the disease itself, if that disease does not substantially limit a major life activity.

The second way the ADA could protect individuals from genetic discrimination would be the “regarded as” prong of the ADA’s definition of disability. In discriminating against an individual with a genetic predisposition, an employer could be found by a court to have regarded an employee as substantially limited in the major life activity of working. Indeed, it was for just such situations that Congress included this prong in the ADA’s definition of disability. However, the Supreme Court in 1999 undermined this intent and dramatically narrowed the possible application of this prong.

In *Sutton v. United Air Lines* and two companion cases, the Court held that to be regarded as being substantially limited in the major life activity of working, the individual with the impairment would need to prove that the *employer regarded him or her* as being precluded from a *broad range of jobs*. For instance, in *Sutton*, the Court found that the employer regarded the petitioners as precluded only from the job of global airline pilot. Because there were many other jobs, like regional pilot or pilot instructor, for which the petitioners were qualified, the Court found the employer did not regard them as being substantially limited in the major life activity of working -- even though the employer refused to hire them as global airline pilots.

The best possible argument, then, for an individual with a genetic predisposition who experiences discrimination in promotion, hiring, or firing, would be to allege that the

employer had acted in an adverse manner out of fear of insurance costs or productivity losses. The individual would then have to prove that the employer *also* believed that *other* employers would have the same reaction and would *similarly* find the individual unqualified to work. Only by establishing such facts could the individual satisfy *Sutton's* requirement that the employer regard the employee as being precluded from a *broad range* of jobs. It is unclear whether courts will allow the individual simply to argue that it is *reasonable to presume* that other employers will feel the same as the employer who engaged in the discrimination.

As you can see, it is far from evident that the ADA will protect individuals with genetic predispositions to disease from discrimination in the employment setting. And it is more than mere speculation to fear that the courts will misapply the ADA's definition of disability and leave these men and women without anti-discrimination protection. Indeed, the courts have acted contrary to Congress' intent in many areas of the Act.

Given our knowledge of the courts' incapacity in this area, it would be foolhardy to *depend* on existing law for the protection of individuals with genetic predispositions to disease. A better policy approach would be to craft language that will make it abundantly clear to the court system that serious medical conditions, and the genetic predispositions to those conditions, are to be protected against discrimination.

S-318 should be passed now so that individuals with genetic predispositions can be confident that they will be protected if they encounter discrimination in health insurance or employment based on their genes.

At the same time, in the coming months I look forward to working with the members of this Committee to restore civil rights protections for the people with already-manifested disabilities and health conditions who have been removed from the ADA's protection by the narrow interpretations of the Supreme Court.

To illustrate the importance of independent legislative action to restore civil rights protections to the people who have been left out by the Supreme Court's *Sutton* trilogy and subsequent cases in the lower courts, I will return for a moment to my own personal example. In my case, as long as the symptoms of my bipolar disorder are well controlled with medication or other strategies I use to manage my condition, I am likely to be found by a federal court to fall outside the ADA's protection. This is a truly bizarre situation. For me to be assured of civil rights protections under the ADA, I would need to let my condition get out of control and possibly require hospitalization. I and countless others are in effect being punished for finding ways to maintain a high level of functioning notwithstanding our medical conditions.

Similarly, in the case of my children, I fear that they will not receive protections under the ADA until they experience symptoms so severe that they become substantially limited in working or some other major life activity. If S-318 becomes law, and I hope it

does, my children will be protected against discrimination as long as their genetic predispositions have not started to manifest in depression or mania. Once they experience their first episode of depression or mania, however, they may lose their civil rights protections. To state a claim under S-318, they would need to show that the covered entity acted on the basis of their genetic information as opposed to their symptoms. To state a claim under the ADA, they would need to show that their condition is so debilitating and uncorrectable that it rises to the level of a disability under the ADA, or that the covered entity regarded them as unable to work for a broad group of employers. There is no good policy reason to make victims of discrimination jump through these kinds of hoops to challenge discriminatory behavior. I look forward to working with this Committee to restore civil rights protections to the entire protected class under the ADA so my family and countless others can be protected against discrimination regardless of the nature of our symptoms and treatment options.

I will close with one more reason to clarify the ADA with additional protective legislation. If S-318 is enacted but the restrictions in ADA protections are not remedied, a person with a genetic predisposition will need to show that their condition has not manifested in order to be protected against discrimination. For many conditions like bipolar disorder, multiple sclerosis, or Alzheimer's disease, it is not always clear when a condition begins to manifest. There is often a period when symptoms occur but a firm diagnosis is not possible. During this period, people may be afraid to seek treatment because they don't want to lose their civil rights protections. To ensure that people will not be afraid to seek treatment and receive a diagnosis, we need to be able to assure them

that, if a condition does manifest, their access to health care and equal employment opportunity will be protected. A bill restoring protections to the broad group Congress originally intended to protect when it enacted ADA would help to address this problem.

Thank you again for the opportunity to testify. I would be happy to answer any questions that you may have.