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EXAMINING ISSUES CONCERNING GENETICS

BEFORE

THE COMMITTEE ON HEALTH, EDUCATION, LABOR AND PENSIONS

UNITED STATES SENATE

FEBRUARY 13, 2002

Introduction

Chairman Kennedy and Members of the Committee, thank you for the opportunity to testify before you today on the subject of genetic discrimination in the workplace. My name is Ronald Adler, and I am president of Laurdan Associates, Inc., a human resource management consulting firm headquartered in Potomac, Maryland. I am a member of the Society for Human Resource Management (SHRM), the world's largest human resource management association with over 165,000 members, and serve on the Society's national Employment Committee. I am a member of the Labor Relations Committee of the U.S. Chamber of Commerce, as well as its Workers' Compensation/Unemployment Insurance and Workplace Trends & International Perspectives Subcommittees. I chair the Maryland Chamber of Commerce's Unemployment Insurance Committee and I am a member of the Chamber's Employment Committee. I also serve as an advisor to insurance companies offering Employment Practices Liability Insurance.

I testify before this committee today as an individual witness, not as a representative of any organization or group, to share my experience and perspective as a human resources practitioner. During my twenty-nine years of experience as a human resources consultant, I have assisted organizations across the nation address and manage a plethora of human resource management issues from auditing employment practices and policies, to developing positive employee relations programs, to ensuring compliance with federal, state, and local labor and employment laws. As a human resources practitioner, I have seen the numerous employment challenges organizations face on a

daily basis as they strive to balance legitimate business needs with the personal concerns of their employees.

In the past few years, I have become increasingly familiar with the emerging issue of genetic information in the workplace. Like many of us, I have been concerned by media reports and anecdotes of individuals who believe that they have been denied employment or insurance coverage based on their genetic makeup. In order to gather some empirical data about the prevalence of employer use of genetic information and to help my clients address this issue, I spearheaded a survey on the use of genetic information in the workplace for the Montgomery County, Maryland chapter of SHRM. Upon completion of the survey, I submitted the results to the Montgomery County (MD) Council, which in December of 2000 became the first local government in the nation to enact legislation prohibiting genetic discrimination in employment. Indeed, the survey results are instructive: Not one of the survey respondents currently conducts genetic testing of its employees, nor seeks to obtain employee genetic information from third-party sources. Furthermore, none indicate that they are likely to do so in the near future. These survey results, although they provide just a snapshot of current employer practice, confirm my experience and observations of client organizations and echo the findings of other national surveys: Employers do not currently seek employees' genetic information and do not plan to do so in the future.

As this committee considers the creation of new public policy regarding the use of genetic information in the workplace, it is my hope, and I am sure the hope everyone in this room today, that the committee takes a cautious, studied, and balanced approach to considering the intended and unintended consequences of legislation in this area. I would

like to focus my testimony on some of the questions that are of particular concern to me as an HR consultant, as well as some of the practical implications of proposed federal legislation prohibiting the knowledge and use of genetic information in the workplace.

However, before I address those issues, I would like to voice my support for the goal of protecting employees against genetic discrimination in the workplace. As the President said in his radio address on this issue last June, any legislation seeking to protect against genetic discrimination must be "fair, reasonable, and **consistent** with existing discrimination statutes." From that perspective, I feel it is imperative that any proposed legislation in this area focus on prohibiting discriminatory conduct, rather than prohibiting the flow of information. From my experience as an HR consultant, I can attest to the difficulty of regulating the flow of information between individuals in the workplace. Indeed, how does one regulate casual conversations between coworkers at the water cooler, or the divulgence of personal health information between an employee and supervisor? More formally, compliance with current employment laws, e.g., the Americans with Disabilities Act (ADA), the Family and Medical Leave Act (FMLA), and workers' compensation, require HR professionals to collect and document medical history information in a manner that current legislative proposals may deem illegal. To avoid opening a Pandora's box of regulatory nightmares, legislation should focus on prohibiting the discriminatory usage of an employee's genetic information, not on punishing an employer's unintended acquisition of such information in the absence of an adverse employment action.

I. THE CURRENT STATUS OF GENETIC INFORMATION USAGE IN EMPLOYMENT

It was just 20 months ago that scientists mapped the human genome. Since then there has been a steady stream of new findings. We stand at the threshold of a new era where the use of genetic information can change medical science from protocols that diagnose and treat to procedures that predict and prevent. Yet, as with other scientific advances, genomic research has given us knowledge before we have wisdom. There are real social, ethical, and legal concerns about the potential misuse or abuse of genetic information. Genetic information that could be used to improve the human condition could lead to discrimination.

In response, legislation has been introduced to prevent genetic discrimination in the workplace by prohibiting the collection and use of employee genetic information for the purposes of making employment-related decisions. Proposed legislation would impose stiff penalties on employers violating these prohibitions, allow for unprecedented damage awards, and permit complainants direct access to the courts.

However, unlike the mountain of documented cases of discrimination that predated previous anti-discrimination laws, there is a dearth of evidence that employers are conducting genetic testing of their employees or using genetic information when making employment decisions. As I mentioned earlier, the results from the Montgomery County SHRM Chapter survey indicate that employers are not discriminating on the basis of genetic information. Further, a national survey on privacy issues conducted in 2000 by SHRM repeated these findings, showing that none of the 722 organizations responding to the survey conducted genetic testing of their employees. An American Management

Association's 2000 Survey on Workplace Testing found similar results: Only seven of the 2,133 companies responding to its survey (or .03%) perform genetic tests. All of these findings support my observations of client organizations across the country: Employers are not rushing pell-mell into the area of genetic testing; they recognize the potential for misuse and abuse of using such information; they understand employee concern over possible future genetic testing and that such testing may have an adverse impact on employee morale; and they are risk adverse to the potential liabilities. More succinctly, on the whole they have no desire to conduct genetic tests. Indeed, what information does exist about employers' use of genetic testing is predominantly anecdotal. Notwithstanding the Burlington Northern Santa Fe Railroad case, the use of genetic testing is by far the exception and nowhere near approaching the rule.

Yet, while the overwhelming data indicate that employers are not collecting or using genetic information for making employment decisions, federal legislation may still be warranted. It has been reported that despite a lack of hard evidence to the contrary, public perception and concern exists that employers and insurers are seeking and using genetic information in a discriminatory manner. As a result, it is contended that individuals may be hesitant to undergo potentially life-saving genetic tests or participate in genetic research based on the fear that they will lose their job or insurance coverage.

To the extent these reports accurately reflect the public's concern, legislation that helps to allay these fears and enable individuals to seek genetic testing and treatment can contribute to the general welfare and public health. However, given the current realities concerning the absence of employers' use of genetic information in making employment decisions, it would be imprudent to prematurely draw lines in the sand. Instead, we

should seek to develop public policy that recognizes the interrelationship and interaction between legislation in this area and the numerous other federal, state, and local statutes already being enforced. We should take the necessary precautions to consider the intended and unintended consequences of our actions.

II. REQUIREMENTS OF THE PROPOSED GENETIC NONDISCRIMINATION LEGISLATION CONFLICT WITH EXISTING EMPLOYMENT LAWS

It is critical in developing genetic discrimination legislation that the requirements of existing employment statutes be considered and that the bill be drafted in a way that does not conflict with current laws or disrupt existing nondiscriminatory employment practices. Again, caution is advised.

From a practical perspective, there is always concern that new employment legislation will be drafted in a vacuum; that consideration will not be given to its impact on and its interaction with existing laws. In assisting my clients, I have experienced this problem firsthand. The interrelationship and interaction among the ADA, FMLA and state workers' compensation law—all imposing differing legal requirements—help demonstrate the problem. Because each law was passed at different times and has a different policy objective, an employer's efforts to comply with one law can easily cause it to violate a provision of the other laws.

It has been my experience that employment laws are most effective when compliance with one law does not contradict the purpose of other laws or does not require employers to violate one law to satisfy another. Unless proposed genetic discrimination legislation recognizes this potential problem, employers will again be

required to solve one more employment issue Gordian knot. I urge the committee as a part of its bill drafting activities to consider the requirements and implications of existing federal, state, and local employment laws when debating the provisions of genetic discrimination legislation. Indeed, this committee has an extraordinary opportunity to enact legislation that provides meaningful protections for employees, that builds on employers' general support for such legislation, and does not further exacerbate the patchwork quilt of conflicting employment laws.

As expressed above, I am concerned about the interaction of proposed genetic employment discrimination legislation with previously enacted employment legislation, specifically but not limited to the ADA, FMLA, and workers' compensation. A fundamental element of each law is the collection of an employee's medical information, which often includes documenting family medical history. This information is required to ensure employer compliance. Under Senate Bill 318, however, such information may be deemed "protected genetic information," and knowledge or use of the information may create liabilities for employers.

For example, under the ADA medical records are utilized to help determine if an employee has an "impairment" that substantially limits one or more major life activities, or has a "record of" such a substantial limiting impairment. Moreover, medical information is often an integral part of determining a reasonable accommodation. Since employers are required to determine whether or not an employee or an applicant has a "disability" within the meaning of the law, the employee's or the applicant's medical information is often required. HR professionals and employers would face an insurmountable challenge in making proper decisions without this information. Yet

S. 318 would impede the collection of relevant medical information and could seriously impact the employer's ability to assist individuals with disabilities in the workplace.

The Family and Medical Leave Act creates similar problems. As you know, the FMLA protects a person with a "serious health condition," which is an illness, injury, impairment, or physical or mental condition that involves one of the following: (1) inpatient care; (2) continuing treatment plus absence from work for more than three calendar days; (3) pregnancy, (4) chronic conditions requiring treatment; (5) permanent or long-term conditions requiring treatment; and (6) multiple treatments for non-chronic conditions. (29 CFR 825.114).

In order for an employer to determine whether an employee qualifies for FMLA leave for the treatment of a serious health condition—whether that condition is manifested by the employee him or herself or by a family member—the employer must collect relevant medical information. This medical information may very well indicate a genetic based health condition. For example, under the FMLA an employee may request intermittent leave to receive radiation treatment for diagnosed breast cancer—a "serious health condition"—and a disease with a known genetic component. In granting this leave request, the employer has just acquired genetic information, a violation under S. 318. Or, if an employee seeks to take leave to care for a child suffering from sickle-cell anemia, a serious hereditary disorder, the employer upon receipt of the leave request will inadvertently obtain genetic information about that employee—again a violation. Genetic discrimination legislation that restricts the flow of all medical information may put employers into a real bind—how do they grant FMLA leave needed by seriously ill

employees without collecting the medical information prohibited by this bill? I urge you to consider these interactions and such legislation's unintended consequences.

The interplay of this bill and the various state workers' compensation law will create a third challenge for employers. Under state workers' compensation laws, medical information is necessary to file a claim and is used to determine whether or not an injury is work-related. Would employers under S. 318 still be able to collect this information? I suggest that, like ERISA, any genetic discrimination legislation include an exception for workers' compensation related claims.

Furthermore, it is possible that in the future genetic testing may become a valuable diagnostic tool in helping employers and governmental agencies determine the sources and causes of injuries and diseases and prescribe the optimum course of action. Under S. 318, the knowledge and use of such information would be prohibited and subject an employer to liability. Because we do not know what benefits may be derived in the future from the use of genetic information, I recommend that legislative efforts be focused on prohibiting the discriminatory use of genetic information, not on the flow of such information.

Parenthetically, the collection and flow of employee information is an important issue for employers. In many respects, employment information is a double-edged sword. With proper information employers can make informed employment related decisions – decisions that they may be legally required to make; without such information decisions become more subjective, often miss the mark, and may subject the employer to claims of negligence. Thus as a general rule, we advise our clients to collect only

information that they may legally use in making employment decisions, to ensure such information is properly retained, and to limit access to such information.

III. S. 318 DEVIATES GREATLY FROM CURRENT EMPLOYMENT DISCRIMINATION LAWS AND CHILLS VALUABLE, GOOD FAITH EMPLOYMENT PRACTICES

Reading S. 318 from the perspective of a human resources consultant, I am struck by the fact that this bill deviates from and is contrary to our nation's other employment discrimination laws. Specifically, S. 318 treats genetic discrimination as a form of discrimination different from discrimination based on race, religion, national origin, sex, age, and disability. First, unlike Title VII as amended and the ADA, which caps damages based on the employer's size, and unlike the Equal Pay Act and other FLSA-based statutes, where damages are limited, S. 318 allows for unlimited compensatory and punitive damages. This design violates one of the guiding principles of our employment laws: Fair and consistent treatment. Individuals who are discriminated against on the basis of their genes should have the same remedies available to them as those discriminated against of the basis of one of the other protected categories. It will be hard for employers and employees to understand why someone who is discriminated against based on their genetic predisposition for a condition that may or may not manifest itself in the future is worthy of special treatment, while someone who is discriminated against because of their **current** disability, or their race, religion, national origin, sex, or age, for that matter is not. The rationale for this inconsistency of treatment -- particularly since there is little evidence of current discrimination based on genetic information – is untenable.

From a practical standpoint, the allowance of unlimited damages will surely lead to increased employment litigation. This will only be exacerbated by my second serious concern with S. 318: the circumvention of the mandatory administrative, investigative, and dispute resolution procedures of the Equal Employment Opportunity Commission (EEOC). Currently, employees and applicants with claims of employment discrimination must file charges with the EEOC or with their state or local human relations commissions. These agencies, which process and investigate claims of employment discrimination, have been successful in recent years in resolving claims during the investigative process or through mediation. There is evidence that the EEOC's mediation activities are having a positive impact on reducing the backlog of employment cases in the courts. S. 318 allows claimants to bypass the EEOC and file immediately in federal or state court, thereby undermining the EEOC's settlement efforts and further clogging the courts' dockets. A 2000 Report by the U.S. Department of Justice states that between 1990 and 1998, employment discrimination cases brought in federal court have tripled, from 8,413 cases in 1990 to 23,735 in 1998.[1] It does not make sense to circumvent a process that has been shown to work.

Considering how much education is still needed for employers and employees alike about the science of genetics, it also makes little practical sense to delay the resolution of many of the inevitable misunderstandings by sending claimants directly to

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[1] *See Civil Rights Complaints in U.S. District Courts, 1990-98,* Department of Justice Bureau of Justice Statistics (January 16, 2000). This does not reflect the many claims filed under parallel state anti-discrimination laws in state courts. In addition to litigated claims, according to figures recently released by the EEOC's Office of Research, Information and Planning, from 1992 through 1999 an average of 81,833 discrimination charges were filed each year. Daily Labor Report (BNA), January 31, 2000, at E1.

the adversarial process of the courts, when many could be easily resolved through mediation. Indeed, in testimony before the House of Representatives Education and the Workforce Committee, Subcommittee on Employer-Employee Relations, in July of last year, Burlington Northern Santa Fe Railroad employee Gary Avery praised the EEOC's administrative procedures in handling his claim against the railroad for conducting genetic testing without his consent. Let us not abandon what clearly already works for both employers and employees.

In summary, I have serious concerns regarding both the unlimited damage awards and the bypassing of the EEOC called for under S. 318. Indeed, given the absence of evidence that genetic discrimination is common, there is no apparent justification for carving out an exception for the rules applicable to all other forms of discrimination.

Finally, various definitions contained in the bill are vague, imprecise, and overly broad, and could lead to serious unintended consequences that may place employers in an untenable position. For example, consider a company sued by its employee for genetic discrimination. Two years before his discharge, the employee casually mentions in a water cooler conversation to a group including a supervisor that his father died of a heart attack at age 47. The family history the heart attack is genetic information, knowledge of which may be attributable to the company even though another supervisor making the discharge decision was unaware of the father's medical history. The same unintended consequences could arise where someone in management reads the obituary of an employee's relation or visits an employee's relative recuperating in a hospital or at home. Do we really want to prevent supervisors from consoling the bereaved or seriously ill employee? It seems the solution may be to focus the provisions of genetic discrimination

legislation on the prevention employment discrimination, not the unintended acquisition and knowledge of an employee's genetic information.

CONCLUSION

Again, I would like to thank the committee for allowing me to testify this afternoon. I commend this committee for examining this complex and extremely important issue, and for its consideration of legislation that is fair, reasonable, and consistent with current employment laws. I urge you in your deliberations to recognize and consider the requirements and mandates placed on employers by existing employment statutes such as the ADA, FMLA, and state workers' compensation. As I noted earlier, this committee has the opportunity to enact legislation that provides meaningful protections for employees; however, it would be a tragedy to rush enactment of legislation that is riddled with unintended consequences, was counterproductive, or failed to achieve its objectives.

I would be happy to help the committee examine and address this issue.