Chair Ishimaru, Vice Chair Griffin, and Commissioners, thank you for the opportunity to speak at this public meeting to provide recommendations on issues to address in regulations implementing the Genetic Information Nondiscrimination Act of 2008 (GINA). I appreciate the opportunity to provide input on these important regulations.

I am Karen Elliott, member of the Society for Human Resource Management (SHRM) and an attorney at Gregory Kaplan PLC where I advise employers and human resource professionals on matters of employment law. Because I am also an employer, I not only advise others on the law, but understand the challenges of implementing it in my own workplace. In addition, I have served as SHRM’s Virginia State Legislative Director and regularly advise HR professionals on issues related to discrimination, health care and privacy issues.
Today, I come before you on behalf of SHRM, the world’s largest association devoted to human resource management. Representing more than 250,000 members in over 140 countries, the Society serves the needs of HR professionals and advances the interests of the HR profession. Founded in 1948, SHRM has more than 575 affiliated chapters within the United States and subsidiary offices in China and India.

Background

SHRM’s long-held policy is that employment decisions should be based on an individual’s qualifications and ability to perform a job, not on characteristics that have no bearing on job performance such as genetics. SHRM is one of the founding members of the Genetic Information Nondiscrimination in Employment Coalition and supported passage of the legislation to prohibit genetic discrimination in employment.

During the legislative process, SHRM raised some concerns about GINA, namely that the Act focused more on the “flow” of genetic information and not necessarily discriminatory conduct. While some of these concerns were mitigated, SHRM continues to remain concerned that employers could find themselves involuntarily in possession of genetic information through the normal course of their workplace operations. We are hopeful that, through this hearing and the rulemaking process, innocent or inadvertent acquisitions of genetic information can be addressed by the Commission.
Acquisition and Disclosure of Information

The clear purpose of Title II of GINA is to prohibit employment discrimination on the basis of genetic information. To fulfill this purpose, involuntary acquisition of genetic information must be clearly differentiated from the purposeful capture of this information for discriminatory purposes. The Commission’s rulemaking can help achieve this balance.

GINA prohibits an employer from discriminating in employment decisions because of genetic information with respect to an employee or a family member of the employee. The statute also prohibits, as an unlawful employment practice, an employer from requesting, requiring, or purchasing genetic information with respect to an employee or a family member of the employee. It further includes six enumerated exceptions for the lawful acquisition of genetic information. The statute then clarifies that any information obtained through one of the enumerated exceptions may not be used for a discriminatory purpose, treated, or disclosed in a manner that violates section 206 on confidentiality. Rulemaking should clarify the scope of each of these exceptions with examples that are meaningful to employers and HR professionals.

As mentioned above, the statute provides exceptions for the acquisition of genetic information. The first “blanket” exception applies when “an employer inadvertently requests or requires family medical history of the employee or family member of the employee.” Clearly circumstances of “inadvertent” requests are not self-explanatory.
Rulemaking—including illustrative examples--can help avoid conflicts over what would otherwise be a subjective judgment regarding the intent behind a request for information.

GINA’s list of enumerated exceptions is far from a complete picture of the ways in which an employer may, willingly or unwillingly, receive genetic information about an employee or family member of an employee. For example, employers commonly receive information from employees through basic, human interactions—a casual inquiry into how an employee, returning from sick leave, is feeling. Indeed, as the Commissioners well know, employees are increasingly serving as caregivers for their parents. It would not be an unusual occurrence for an employee to offer information about his or her parent’s illness and treatment as part of a conversation with the supervisor about the amount of time off the employee needs.

Other examples of information flow in the office setting include situations in which an employee seeks help from HR to get reimbursement from the health care provider for a medical or genetic test. In this situation, the employer’s attempt to assist the employee with a billing dispute means that the employer now has knowledge of the employee’s genetic information. To help clarify GINA’s applicability in these situations, rulemaking should fill the gaps to the extent allowed by the scope of the Commission’s authority.
In each of these examples, the employer now possesses genetic information that it did not seek, inadvertently request, or require. Information not sought by the employer and self-disclosed by the employee should not subject an employer to the prohibitions of the Act. In fact, much of the information received by employers about family history may be completely unrelated to the employee’s health, is usually anecdotal, and often erroneous. No employer should be at risk of liability for receiving this type of information even if it is deemed “genetic.”

The exceptions section similarly fails to address all situations related to FMLA needs. Although the statute provides an exception where an employer seeks information to comply with an FMLA certification for both the federal law and any similar state law, it does not consider local mandates for family and medical leave, such as those required by the City of San Francisco. Further, many employers provide leave for illnesses not covered by the FMLA, or beyond what is mandated by the FMLA for medical and family reasons or provide similar leave but fall below the 50 employee threshold under the FMLA. In order to administer these additional leave programs, employers routinely require employees to provide documentation of the need for leave. I think we can all agree that we should encourage employers who wish to provide leave benefits beyond what is required by law. To that end, I would encourage EEOC to include these FMLA-related programs when clarifying application of the exceptions.
An additional complication arises under GINA’s definition of “genetic information” which means “the manifestation of a disease or disorder in family members of such individual,” and the prohibition against requesting or requiring that information. In many instances, especially among the thousands of businesses with fewer than 50 employees, physician’s notes are commonly requested to excuse absences. Although not requested, physicians will sometimes volunteer medical information. Section 210 of GINA states that certain medical information is not genetic information. Because physician’s notes (outside of any FMLA certification) are not addressed, it is difficult to know when, if or how those notes might violate the law or qualify as an exception under Section 210. The regulations should clarify the breadth of exceptions permitting acquisition of all such information, if collected pursuant to law and retained in confidential files.

In addition, although GINA provides exceptions for complying with federal and state FMLA, it does not adequately address similar workplace laws that more often involve an employer’s need for the same information such as discussing accommodations under the Americans with Disabilities Act (ADA) or discussions regarding health insurance coverage under the Health Insurance Portability and Accountability Act (HIPAA) or COBRA. The interplay of the GINA and the ADA and HIPAA creates significant complexities for HR professionals. Employer efforts to make timely and accurate determinations regarding requests for accommodations or claims brought under the current law should not be inhibited or made illicit.
Lastly, GINA allows disclosure of genetic information in disparate and narrowly-construed situations. While allowing for public health and health research-related disclosure, GINA does not address disclosure of genetic information in health-related emergencies. An employer, having knowledge of an employee’s genetic or family health information should be able to share that information with the medical personnel who respond to a call for help at the worksite. The ADA includes an exception for this type of situation. SHRM recommends that GINA allow for a similar exception.

Recommendations

The Commission, in its rulemaking, should provide guidance on situations that do not fall squarely into the exceptions enumerated in the statute. It is necessary for the Commission to clarify the exceptions to the prohibition on an employer requesting, requiring, or purchasing genetic information to ensure the following:

- Information not sought by the employer, and information that is self-disclosed by the employee should be covered under the first exception.
- The exception allowing for the acquisition and disclosure of information to comply with federal and state FMLA should be clarified to include information used by an employer to comply with employer-provided sick or family leave that is not FMLA qualifying, local FMLA laws, workers’ compensation forms, ADA accommodations or discussions regarding health insurance coverage under HIPAA or COBRA.
• Clear guidance provided by the Commission to employers and employees about their rights and responsibilities under the Act.

• Clarify allowable disclosure to include those allowed by the ADA in health-related emergency situations.

**Conclusion**

SHRM supports the policy of nondiscrimination in employment based on an individual’s genetic makeup or pre-disposition to certain diseases or conditions. Employment decision should be based on an individual’s qualifications and ability to perform a job, not on the basis of other characteristics or imputed attributes that have no bearing on job performance.

SHRM is looking forward to working with the Commission on the successful implementation of GINA. On behalf of SHRM, I thank you for the opportunity to testify today and would be happy to answer any questions.