

May 1, 2009

**VIA ELECTRONIC MAIL:** <http://www.regulations.gov>

Stephen Llewellyn  
Executive Officer  
Executive Secretariat  
Equal Employment Opportunity Commission  
131 M Street, NE  
Suite 6NE03F  
Washington, DC 20507

**RE: Comments in Response to RIN 3046-AA84, the Proposed Regulations Under the Genetic Information Nondiscrimination Act of 2008, 29 CFR 1635, Request for Public Comment Published at 74 Fed. Reg. 9056 (March 2, 2009)**

Dear Mr. Llewellyn:

Thank you for the opportunity to submit comments on the Equal Employment Opportunity Commission's (EEOC's or Commission's) proposed rule that would implement Title II of the Genetic Information Nondiscrimination Act of 2008 (GINA).<sup>1</sup> We respectfully submit these comments on behalf of the Chamber of Commerce of the United States (the Chamber), the Society for Human Resource Management (SHRM), the College and University Professional Association for Human Resources (CUPA-HR), the National Public Employer Labor Relations Association (NPELRA), the Associated Builders and Contractors, Inc. (ABC), and the National Federation of Retailers (NRF).

#### **STATEMENT OF INTEREST**

The Chamber is the world's largest business federation, representing more than 3 million businesses and organizations of every size, sector and region.

SHRM is 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.

CUPA-HR serves as the voice of human resources in higher education, representing more than 11,000 HR professionals at over 1,700 colleges and universities across the country, including 90 percent of all U.S. doctoral institutions, 70 percent of all master's institutions, more than half of

---

<sup>1</sup> *Regulations Under the Genetic Information Nondiscrimination Act of 2008*, 29 C.F.R. 1635, RIN 3046-AA84, 74 Fed. Reg. 9056 (March 2, 2009).

all bachelor's institutions and 500 community colleges. Higher education employs 3.3 million workers nationwide, with colleges and universities in all 50 states.

NPELRA is the premier organization for public-sector labor relations and human resource professionals, with a network of state affiliates with over 2,900 members around the country. The governmental agencies represented in NPELRA employ more than 4 million workers in federal, state and local government.

ABC is a national construction industry trade association representing more than 25,000 contractors, subcontractors, materials suppliers and related firms in 79 chapters across the United States. ABC member contractors employ more than 2.5 million skilled workers, whose training and experience span all of the 20+ skilled construction trades. The merit-shop workforce comprises over 80 percent of the commercial and industrial construction industry, the vast majority of which are classified as "small businesses" by the U.S. Small Business Administration.

NRF is the world's largest retail trade association, with membership that comprises all retail formats and channels of distribution including department, specialty, discount, catalog, Internet, independent stores, chain restaurants, drug stores and grocery stores, as well as the industry's key trading partners of retail goods and services. NRF represents an industry with more than 1.6 million U.S. retail establishments, more than 24 million employees — about one in five American workers — and 2008 sales of \$4.6 trillion. As the industry umbrella group, NRF also represents more than 100 state, national and international retail associations.

Collectively, we represent large, small, private, nonprofit and public employers operating in every sector of the economy. Our members are responsible for ensuring compliance with Title II of GINA, and thus are impacted directly by EEOC's proposed GINA regulations. We also bring expertise on practical, compliance and legal issues employers may face in implementing the regulations and coordinating GINA with existing laws, employment policies and employee benefit programs.

### **COMMENTS ON THE PROPOSED REGULATION**

We strongly support genetic nondiscrimination and confidentiality and believe 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. Several of our organizations worked with the drafters of GINA and other interested stakeholders in an effort to ensure that any law enacted prevents discrimination and protects privacy, while also giving due consideration to existing protections and interaction with existing disability, leave and benefits laws and voluntary employee benefits programs.

While many improvements were made to GINA through the legislative process over the years, we remain concerned that an overly broad GINA regulatory framework will result in serious, negative, albeit unintended, consequences. We are particularly concerned that employers and employees will struggle to discern genetic information from general medical information about health status, disability and manifested disease. Without a clear definition that separates genetic information from other medical information and clearly defined rules on permissible acquisition,

use and disclosure of information, GINA will lead to unnecessary litigation and hamper employers' ability to offer important employee benefits and comply with other laws.

With this in mind, we respectfully submit the following comments on specific sections of the proposal regulations.

*Section 1635.2(c) – Definition of Employee*

In defining employee, GINA section 201(2)(A)(i) (42 U.S.C. § 2000ff(2)(A)(i)) references definitions in section 701(f) of the Civil Rights Act of 1964 (42 U.S.C. § 2000e(f)), which defines the term “employee” as “an individual employed by an employer.”

The Commission states in the preamble to the proposed regulation that “the Supreme Court has held that the term ‘employee’ under Title VII includes former employees ... [a]ccordingly, the proposed regulation makes clear that the term ‘employee’ includes ... a former employee.” 74 *Fed. Reg.* 9056 (March 2, 2009). In support of its claim, the Commission cites the Supreme Court’s decision in *Robinson v. Shell Oil Co.*, 519 U.S. 337 (1997). While we agree the Commission should apply the *Robinson* standard, that standard does not support including the term “former employee” in 1635.2(c), and the Commission should remove the term from the definition.

The issue before the Court in *Robinson* was whether the term “employees” as used in section 704(a) of the Civil Rights Act of 1964 (42 U.S.C. § 2000e-3(a)) includes former employees or just current employees. Section 704(a) is Title VII’s anti-retaliation provision—very similar to section 207(f) of GINA (42 U.S.C. § 2000ff-6(f)).

While the Court concluded that, “former employees are included within section 704(a)’s coverage,” it found section 701(f) – the provision referenced by GINA – is ambiguous on the issue. *Id.* at 346 and 343. Specifically, the Court said since the term “employees” under Title VII “includes former employees in some sections, but not in others, the term standing alone is necessarily ambiguous and each section must be analyzed to determine whether the context gives the term a further meaning that would resolve the issue in dispute.” *Id.* at 343-344.

Given GINA’s specific reliance on section 701(f), the Court’s approach in *Robinson* should be applied to GINA section 201(2)(A)(i) (42 U.S.C. § 2000ff(2)(A)(i)).<sup>2</sup> As a result, the determination as to whether the term “employee” includes former employees in any given GINA provision should be made through analysis of the specific provision and whether the context supports such a conclusion. In other words, while *Robinson* is properly read to include former employees within the definition of employees for anti-retaliation provisions, it does not address the general nondiscrimination provisions and should not be so extended in GINA. We urge the Commission to remove the term “former employee” from section 1635.2 and instead note in the preamble to the final rule that determination as to whether the term includes former employees will be made on a case-by-case basis in accordance with *Robinson*.

---

<sup>2</sup> See also S. Rep. No. 110-48 at 27 and H. Rep. No. 110-28 at 35, both stating “As a guiding principle, the Genetic Information Nondiscrimination Act of 2007 is designed to extend to individuals in the area of genetic discrimination the same procedures and remedies as are provided under Title VII of the Civil Rights Act of 1964, as amended.”

*Section 1635.3(b) – Definition of Family Medical History*

Section 1635.3(b) of the proposed regulation defines “family medical history” as “information about the manifestation of disease or disorders in family members of the individual.” We urge the Commission to modify the definition so it reads “inheritable disease or disorder,” as this would more accurately reflect the information GINA is intended to cover. We do not believe that Congress intended non-inheritable conditions, such as colds and the flu, upset stomachs, chicken pox, etc., in family members to be part of the family medical history.

As the Commission notes, the Senate Report states that Congress included family history in GINA’s coverage because it “could be used as a surrogate for a ‘genetic trait,’ ... and that the definition of ‘genetic information’ had to include ‘family medical history’ to prevent a covered entity from making decisions about an individual’s health based on the existence of an *inheritable* disease of a family member.” 74 *Fed. Reg.* 9059 (March 2, 2009) (citing S. Rep. No. 110-48 at 16 and 28) (emphasis added). H. Rep. No. 110-28 at 36.

Similarly, the House Committee Report on H.R. 493 states, “the Committee realizes that a family medical history could be used as a surrogate for genetic traits, [as a] consistent history of a *heritable* disease in a patient’s family may be viewed to indicate that the patient himself or herself is at increased risk of that disease.” Likewise, in January 2007, Rep. Slaughter, a principal sponsor of H.R. 493, testified that according to her understanding of this bill’s purpose as it applied to health insurance and health plans, GINA was to focus “*solely on a genetic predisposition to develop a disease in the future.*” (emphasis added). Since information about non-inheritable conditions in family members does not reveal a “genetic predisposition to develop disease in the future,” the Commission should specifically make clear that GINA does not cover information about non-inheritable conditions and specifically exclude such information in the definition of “family medical history.”

Another issue that may arise under 1635.3(b) is where two or more family members work for the same employer. In such circumstances, when an employer obtains medical information from one employee, it should not be deemed family medical history of the related employee. A contrary reading would mean many types of ordinary employee health information would then be prohibited simply because family members are also employees. This should be made clear in the regulations.

*Section 1635.3(c) and (f) – Definitions of Genetic Information and Genetic Test*

One of the most challenging aspects of GINA compliance will be distinguishing genetic information from general medical information about health status, disability and manifested disease, particularly where the genetic information is included as part of a more comprehensive medical record. Where an employer is simply trying to accommodate a disability or leave request or address other issues related to current health status, employee benefits or health and safety, it will be extremely difficult to segregate genetic information. In short, it will be exceptionally challenging for employers to separate genetic information from other health information provided by individuals, doctors or other third parties, and in trying to separate such information, the employer may face other legal, ethical or practical problems.

If the Commission takes an overly broad approach to the term “genetic information” in the regulations, it will further confuse and complicate this already challenging task. As we stated at the beginning of our comments, without a clear definition that separates genetic information from other medical information and clearly defined rules on permissible acquisition, use and disclosure of information, GINA will lead to unnecessary litigation and hamper employers’ ability to offer important employee benefits and comply with other laws.

With this in mind, we recommend the Commission make clear in the regulations that “genetic information” under GINA includes only information about inherited alterations in genetic material or genes that are associated with increased risk of a disease or illness in that person that is asymptomatic. Such interpretation is consistent with the text and the intent of GINA. As noted above in our comments on Section 1635.3(b), Congress intended GINA to apply “*solely on a genetic predisposition to develop a disease in the future,*” not information about a person’s current health condition.<sup>3</sup>

As applied to family medical history, this means the term should only include information about inheritable conditions, as mentioned in our comments above on section 1635.3(b). Also, again as mentioned in our comments on section 1635.3(b), when an employer obtains medical information from one employee, it should not be deemed family medical history of a related employee.

With respect to genetic tests, the definition should be focused on capturing tests that meet the statutory definition and reveal information about heritable conditions, not on tests for current health conditions or status. Thus, we agree with the Commission that tests for “infectious or communicable diseases” and routine tests, such as “complete blood counts, cholesterol tests, and liver function tests,” are not genetic tests. 74 *Fed. Reg.* 9059 (March 2, 2009).

While in certain circumstances information about genetic tests or family medical history that may confirm a diagnosis of a current condition would fall within the definition of genetic information, the fact that the individual has the condition would not.<sup>4</sup> For example, if an individual with Huntington’s disease who is displaying symptoms has a genetic test to confirm the presence of the genetic variant, information about the test would be considered genetic information as it is a test within the statutory definition of genetic test that reveals information about an inheritable condition. The fact that an individual has Huntington’s disease and information about his or her symptoms, however, is information about a manifested condition and therefore is not genetic information under GINA, even though Huntington’s has a genetic basis. Likewise, the fact that an employee’s family member has cystic fibrosis is genetic information (unless that family member is also an employee); but the fact that the employee has

---

<sup>3</sup> See 74 *Fed. Reg.* 9059 (March 2, 2009) (citing S. Rep. No. 110-48 at 16 and 28) and H. Rep. No. 110-28 at 36, both noting GINA is focused on inheritable conditions.

<sup>4</sup> Title I of GINA specifically excludes from the definition of genetic test “an analysis of proteins or metabolites that is directly related to a manifested disease, disorder or pathological condition...” 29 U.S.C. § 1191b(d)(7). While that exemption is not included in Title II’s definition of genetic test, section 210 of Title II states that employers will not “be considered to be in violation of this title based on the use, acquisition, or disclosure of medical information that is not genetic information about a manifested disease, disorder, or pathological condition of an employee ... including a manifested disease, disorder or pathological condition that has or may have a genetic basis.” 42 U.S.C. § 2000ff-9.

the same condition is not genetic information, even if the family history was instrumental in the diagnosis.

This distinction is a subtle but important one. We provide further detail on this issue in our comments below on section 1635.3(g) of the proposed regulation.

*Section 1635.3(g) – Definition of Manifestation or Manifested*

We support the EEOC’s effort to define the terms “manifestation or manifested” in section 1635.3(g) of the regulations. Title II of GINA is intended to protect employees from misuse of information that may reveal whether the employee is at risk for developing a specific disease or disorder, including information about inheritable manifested diseases or disorders in the employee’s family members (family medical history).<sup>5</sup> As we noted above in our comments on sections 1635.3(b),(c) and (f), however, GINA is not intended to apply to information about an employee’s own current health condition—including any manifested conditions that have a genetic basis.<sup>6</sup> Thus, determining what constitutes a manifested condition is crucial in identifying what information falls within GINA’s purview and what information does not.

As the Commission points out, however, GINA itself does not specifically define the terms “manifested” or “manifestation.” 74 *Fed. Reg.* 9060 (March 2, 2009). As a result, we welcome a definition in the regulation, as long as it is consistent with the text and intent of the act. Unfortunately, as drafted, section 1635.3(g) is consistent with neither.

Proposed section 1635.3(g) defines the terms “Manifestation” or “Manifested” as:

“a disease, disorder, or pathological condition that an individual has been or could reasonably be diagnosed with ... by a health care professional with appropriate training and expertise in the field of medicine involved. For the purposes of this part, a disease, disorder, or pathological condition is not manifested if the diagnosis is based principally on genetic information or on the results of one or more genetic tests.”

The last sentence of the definition directly conflicts with GINA section 210, which states that employers will not “be considered to be in violation of this title based on the use, acquisition, or disclosure of medical information that is not genetic information about a manifested disease, disorder, or pathological condition of an employee ... *including a manifested disease, disorder or pathological condition that has or may have a genetic basis.*” 42 U.S.C. § 2000ff-9 (emphasis added).<sup>7</sup>

---

<sup>5</sup> GINA section 201(4) defines genetic information as, among other things, “information about ... the manifestation of a disease or disorder in family members of such individual.” 42 U.S.C. §§ 2000ff (4).

<sup>6</sup> GINA Section 210 states that employers will not “be considered to be in violation of this title based on the use, acquisition, or disclosure of medical information that is not genetic information about a manifested disease, disorder, or pathological condition of an employee ... *including a manifested disease, disorder or pathological condition that has or may have a genetic basis.*” 42 U.S.C. §§ 2000ff (4) and 2000ff-9. *See also* note 3.

<sup>7</sup> If the Commission’s intent is to capture possible situations where an individual lacks symptoms, but nonetheless has a “manifested” condition that can only be diagnosed via genetic tests performed “by a health care professional

The potential adverse impact of section 1635.3(g) is real, as there appears to be a host of manifested diseases and disorders that rely on genetic tests for diagnosis, and the list is likely to grow.<sup>8</sup> Whether the diagnosis for these diseases and disorders are “principally based on genetics information” is a question that is sure to invite litigation and chill employers from engaging in otherwise-lawful activity, such as post-employment examinations or other lawful inquiries into an individual’s current health status.

Moreover, as drafted, section 1635.3(g) is contrary to the intent of GINA. The legislative history on section 210 states “[t]he section makes clear the Act does not extend to manifested diseases and illnesses.” H. Rep. No. 110-28 at 44. Yet, section 1635.3(g) would result in GINA possibly applying to many manifested conditions with a genetic basis that are or will be in the future diagnosed via genetic tests or other genetic information.

This would expose employers to potential liability for otherwise legitimate use, acquisition or disclosures of an individual’s current health care information—something for which GINA was never intended. For example, the provision could interfere with an employer’s ability to use post-offer medical examination for the “purpose of determining an applicant’s current ability to perform a job” –something the preamble specifically states GINA will not do. 74 *Fed. Reg.* 9061 (March 2, 2009).

In addition, section 1635.3(g) could result in certain information about current diseases and disorders in employees’ family members being excluded from GINA’s purview (i.e., employers might not be restricted from requesting or using this information).

For the aforementioned reasons, we urge the EEOC to remove the following language from section 1635.3(g): “For the purposes of this part, a disease, disorder, or pathological condition is not manifested if the diagnosis is based principally on genetic information or on the results of one or more genetic tests.”

#### *Section 1635.8(a) – General Prohibition on the Acquisition of Genetic Information*

GINA section 202(b) makes it unlawful “for an employer to request, require or purchase the genetic information” of an employee or an employee’s family member, except in limited circumstances. 42 U.S.C. § 2000ff-1. To violate the provision, the employer must undertake the *intentional* act of requesting, requiring or purchasing *genetic* information. Thus, the employer would not violate section 202(b) by overhearing a discussion about an employee’s genetic information or otherwise passively receiving the information, as there was no request on the employer’s part. Nor would an employer violate 202(b) by making a general request for health care or other information, unless the request was specifically intended to elicit genetic information.

---

with appropriate training and expertise in the field of medicine involved,” the Commission should attempt to address the proper handling of such circumstance via examples in the preamble or in later guidance.

<sup>8</sup> For example, see <http://www.genedx.com/tests.php>; cystic fibrosis at <http://www.cff.org/AboutCF/Testing/GeneticCarrierTest/> and [http://www.nhlbi.nih.gov/health/dci/Diseases/cf/cf\\_diagnosis.html](http://www.nhlbi.nih.gov/health/dci/Diseases/cf/cf_diagnosis.html); and hereditary hemochromatosis at <http://mostgene.org/gd/gdvol14c.htm>.

We raise this issue because the preamble suggests that passive acquisition of genetic information by an employer would be deemed an equivalent to the overt act of the employer requesting such information. This is an overly broad reading that conflicts with the clear language of 202(b).<sup>9</sup> An employer should not be considered to have violated 202(b) where an employee discloses genetic information in the absence of a request. For example, where an employee seeks help from HR to get reimbursement from the health care provider for a genetic test, the employer has not requested the information and therefore has not implicated 202(b).

Similarly, the preamble suggests that an employer's request for health care information in the course of complying with any laws or administering employee benefits could be deemed a request for genetic information, even though the employer had no intent to elicit genetic information. Again, this is in conflict with the clear language of 202(b).

We urge the EEOC to make clear in the preamble and the regulations that 202(b)'s prohibitions only apply to situations where the employer undertakes the intentional act of requesting, requiring or purchasing genetic information, not where the employee volunteers information.

Another concern is the impact of section 1635.8(a) will have on post-offer medical examinations that are currently compliant with the Americans with Disabilities Act. Many of us have members who employ individuals that must meet certain physical requirements in the course of their work, such as police, firefighters, other public safety officers or private-sector workers whose physical condition is important for safe performance of their duties. A post-offer medical exam is often, if not always, part of the hiring process for these positions.

The objective of these medical exams from the employer perspective is not to elicit genetic information about an individual, but to ensure the applicant is able to safely perform his or her duties. These examinations serve an important goal of ensuring the safety of the employee and the public. The regulations should strive to provide clarity on how employers may obtain information pertinent to an employee's safe job performance, while also complying with GINA.

The International Public Management Association for Human Resources (IPMA-HR), which also represents public employers, eloquently defines the problem and provides a reasonable solution, as set forth below:

Generally cities do not dictate to the medical practitioner[s] how to conduct their exam of the patient to determine fitness for duty. This is a decision made by the licensed medical provider, who may use family history inquiry as a standard procedure for medical evaluation. Cities generally do not have access to their medical provider's forms and procedures related to conducting exams.

---

<sup>9</sup> While section 202(b) is entitled "Acquisition of Information," the language in the 202(b) clearly only applies when the employer requests, requires or purchases information. *See Bhd. of R.R. Trainmen v. Balt. & Ohio R.R.*, 331 U.S. 519, 528-29 (1947) (the title of a statute and the heading of a section cannot limit the plain meaning of the text).

Some cities may not even be aware that their medical provider is asking family medical history questions – but will still be subject to liability if they do. The regulation places non-medically trained employers in the awkward (and perhaps untenable position) of explaining/educating medical professionals on how to best conduct an exam of a patient presented to them. Our suggestion to remedy this would be to allow the medical provider under the regulations to ask these questions, so long as this family history information is not transmitted to the employer.

The Minnesota League of Cities’ best practices for examinations is illustrative of how IPMA-HR’s solution might work as applied:

As a general rule, the city should not ask for any more information than it absolutely needs or share information with anyone who does not have a clear business reason for knowing the information. For example, some cities conduct post-offer, pre-employment physical examinations on job candidates. ***The best practice for such examinations is to provide the doctor or clinic with a list of the essential functions of the position and ask them to state only whether or not the candidate can perform those functions.*** Additional medical information is only needed if the city must attempt to provide reasonable accommodation or determine whether an applicant would be a direct threat to the safety of themselves or others.

Under such circumstances, employers are not requesting or requiring genetic information, but are simply seeking confirmation that the employee is capable of performing the essential functions of his or her job. This concept is equally applicable in other situations where the employer may be otherwise lawfully seeking information about the employee’s ability to perform his or her job, such as a fitness-for-duty certification following a medical leave or accident or in response to an accommodation request. The regulations should make clear such inquiries by the employer are lawful under GINA, even though the medical provider may use family history as a standard procedure for medical evaluation (and could face legal or ethical dilemmas for failing to do so). In doing so, the Commission would be properly interpreting 202(b) as well as GINA sections 206(c),<sup>10</sup> 209(a)(1),<sup>11</sup> 209(b)(4), 209(b)(6), and 210, all of which envision the employer as being able to rely on a medical professional’s accurate assessment of whether the employee is able to

---

<sup>10</sup> GINA section 206(c) applies where a HIPAA-covered entity provides services and there is not communication between such providers and the employer that involves genetic information covered by 202(b).

<sup>11</sup> The provision states “nothing in this title shall be construed to ... limit the rights and protections under any Federal or State statute that provides equal or greater protection to an individual ... including the Americans with Disabilities Act...” Among other things, the ADA requires the employer to provide an accommodation that enables a qualified disabled individual to perform the essential functions of the position. *See EEOC Enforcement Guidance on Reasonable Accommodation and Undue Hardship Under the Americans with Disabilities Act at <http://www.eeoc.gov/policy/docs/accommodation.html>*. To meet this obligation under the ADA, an employer must identify whether an individual is qualified, disabled and able to perform the essential functions with an accommodation.

perform his or her job. *See* 42 U.S.C. §§ 2000ff-1(b), 2000ff-5(c), 2000ff-8(a)(1),(4) and (6), and 2000ff-9.

As a final note on section 1635.8(a), we want to emphasize that in many cases GINA section 206(c) would apply. As the Commission notes, “nothing in section 1635.8 should be read as applying to or otherwise restricting the use or disclosure of genetic information that is protected health information subject to the HIPAA Privacy Rule.” 74 *Fed. Reg.* 9062 (March 2, 2009).

*Section 1635.8(b)(1) – The Inadvertent Exception to the Acquisition of Genetic Information*  
Section 1635.8(b)(1) of the proposed regulation provides several examples of situations that the EEOC believes fall within the GINA section 202(b)(1) exception. Section 202(b)(1) exempts from GINA’s prohibition barring employers from requesting, requiring or purchasing genetic information, situations “where an employer inadvertently requests or requires family medical history of the employee or the family members.” 42 U.S.C. §§ 2000ff-1(b)(1).

The examples provided in sections 1635.8(b)(1)(i)-(vi) seem to apply to situations where the employer either passively received genetic information through overhearing a conversation or received genetic information from an employee in response to a general health inquiry that did not solicit genetic information. While the specific facts and the intention of the employer will be determinative, these examples largely appear to be situations where the employer has not acted in violation of 202(b)—not because of an exemption, but because the employer has not requested, required or purchased genetic information. As we noted in our comments on proposed section 1635.8(a) above, passively receiving genetic information with no overt act on the employer’s part simply is not tantamount to requesting, requiring or purchasing genetic information. Similarly, absent a showing of intent by the employer to elicit genetic information, an otherwise lawful request by an employer for general health information does not become unlawful under section 202(b) simply because the employee provides genetic information in response.<sup>12</sup>

Consequently, we suggest the Commission clarify in the regulations that these examples are situations where an employer has not implicated GINA 202(b) because it has not requested, required or purchased genetic information. The Commission should develop and provide within the final regulation other examples of situations that fall within 202(b)(1) (i.e., where the employer requested or required genetic information but did so inadvertently).

Webster defines inadvertent as being “not duly attentive.” We believe that 202(b)(1) would apply to situations where the employer failed to take care and as a result accidentally solicited genetic information. The example in 1635.8(b)(1)(vi) where the employer inquired about the health of an employee’s family members is illustrative of a inadvertent request. Such a request might be made in casual “water cooler” conversation or incidental to a conversation about requests for leave to care for the family member or bereavement leave. For example, an employee who seeks bereavement leave following the death of his or her mother may receive a

---

<sup>12</sup> While the exception in 202(b)(1) certainly strengthens the argument that a request must intend to solicit genetic information to violate 202(b), the 202(b) language in itself as well as other GINA provisions that envision continuation of currently lawful inquiries into an employee’s current health status, make clear 202(b) only applies to situations where an employer intends to solicit genetic information.

sympathetic response from a supervisor “I just saw you with her last week, what happened?” The intent of the supervisor may have been to sympathize, but the question appears to be soliciting information about how the family member died, which could be deemed a request for genetic information. Conversations with an employee regarding work performance may develop into discussions concerning outside stresses affecting the employee, such as the health of family members or the employee’s own genetic information. GINA’s legislative history makes clear that the aforementioned examples are intended to be exempt under 202(b)(1).<sup>13</sup>

To the extent the Commission disagrees with our reading of 202(b) and believes that any employer acquisition of genetic information falls within 202(b)’s ambit, we would urge it to interpret 202(b)(1) broadly and retain the existing examples set forth in 1635.8(b)(1)(i)-(vi). We also ask the EEOC to convey that the examples are not an exhaustive or complete list of what would fall within 202(b)(1).

*Section 1635.8(b)(2) – Wellness Program Exception to the Acquisition of Genetic Information*

Wellness programs are an important benefit employers offer to improve the lives and morale of employees and control health care benefit costs. Wellness plans are not intended to be part of an effort to collect genetic information or discriminate against employees because of such information.

With this in mind, we encourage the Commission to define “voluntary” under GINA in a manner that is consistent with the Health Insurance Portability and Accountability Act (HIPAA) nondiscrimination requirement.<sup>14</sup> HIPAA permits certain limited inducements to voluntary wellness programs. The HIPAA limitations ensure programs are voluntary by allowing inducements, but barring any reward or penalty that is “so large as to have the effect of denying coverage or creating too heavy a financial penalty on individuals who do not satisfy an initial wellness program standard that is related to a health factor.” 71 *Fed. Reg.* 75018 (December 13, 2006). We think this approach is consistent with the ADA and GINA.

In addition, the preamble contains the following, “[A]lthough not stated in the proposed regulation, a covered entity that receives ‘aggregate’ information may still violate GINA where the small number of participants, alone or in conjunction with other factors, makes an individual’s genetic information readily identifiable.” 74 *Fed. Reg.* 9062 (March 2, 2009).

---

<sup>13</sup> The Senate and House Reports on GINA state, “the first exception addresses the so-called ‘water cooler problem,’ in which an employer unwittingly receives otherwise protected genetic information in the form of family medical history **through casual conversations with a worker**. The committee recognizes that conversations among co-workers about the health of a family member are common and intends to prevent such normal interaction from becoming the basis of litigation under this Act. **Without the exception, the committee is concerned that discussion in the workplace of a family member’s health condition that is genetically based could be interpreted as an employer requesting or requiring genetic information from an individual**. Under the legislation, an employer, labor organization, employment agency, or joint labor-management committee will not violate the ban on acquiring genetic information where it ‘inadvertently requests or requires family medical history’ of the individual or family member of the individual.” (emphasis added) S. Rep. No. 110-48 at 29 and H. Rep. No. 110-28 at 36. While the preamble indicates the reports address situations in which the employer overhears workers, we found no such language at the citation provided, the above quote being the complete language on Section 202(b)(1) at the provided citation. *See id.*; 74 *Fed. Reg.* 9061 (March 2, 2009).

<sup>14</sup> *See* Department of Labor Field Assistance Bulletin No. 2008-02 at <http://www.dol.gov/ebsa/pdf/fab2008-2.pdf>.

An employer should not be liable if it meets the requirements in GINA 202(b)(2) simply because it may be able to identify an employee based on the aggregate information. By its terms, the statute prohibits only disclosing “the identity of specific employees,” which suggests a more narrow reading than EEOC is giving the provision. *See* 42 U.S.C. §§ 2000ff-1(b)(2)(D). Many employers or wellness programs are small enough that information could possibly identify an individual employee. Creating liability in this situation is not consistent with the text of 202(b)(2) and would discourage employers from offering wellness programs.

Lastly, it is important to recognize in the discussion of wellness programs that GINA section 206(c) renders provisions like GINA section 202(b)(2) surplus in circumstances where a HIPAA-covered entity provides the health or wellness service and there is no communication between such providers and the employer. *See* 42 U.S.C. §§ 2000ff-5(c). Of course, the two sections must be read consistently, therefore 202(b)(2) cannot be read to negatively implicate wellness programs that are authorized and encouraged by section 206(c).

*Section 1635.8(b)(4) – Limited Exception for the Purchase of Genetic Information*

GINA section 202(b)(4) provides an exception to the 202(b) restriction on purchasing of genetic information “where the employer purchases documents that are commercially and publicly available (including newspapers, magazines, periodicals and books, but not including databases or court records) that include family medical history.” *See* 42 U.S.C. §§ 2000ff-1(b)(4).

We agree with the Commission that this exception should be expanded to genetic information beyond family history as the employer could just as easily see an article in a publication he or she purchased that discussed individuals living with the breast cancer gene as an obituary or article on detailing someone’s family history.

We also agree with the Commission that the rule should be read to include purchase of electronic media that is commercially and publicly available, such as purchased online subscriptions to newspapers, movies, etc.

The Commission has requested that those commenting address whether the exception should apply to other sources that are not databases or court records, such as social networking websites. To the extent the employer purchases access to such a site, we think the exception should apply. Where access to the site is free or the online or other publication is free, we do not think the employer has implicated 202(b) because it has not requested, required or purchased anything about the employee. To the extent the Commission disagrees with our reading of 202(b), we would urge it to include free sites and other free publicly available materials in the universe of publications exempt under 1635.8(b)(4).

Obviously, an employer would violate 202(b) by using communication vehicles on social sites to request genetic information from someone about employees or employees’ family members regardless of whether the site was free or purchased, as this would be a request for information.

*Section 1635.8(b)(5) – Exception for Genetic Monitoring*

As with the section of the preamble on wellness programs, the preamble on section 1635.8(b)(5) suggests an employer that receives “aggregate” information as part of monitoring may still violate GINA where the small number of participants, alone or in conjunction with other factors, makes an individual’s genetic information readily identifiable.

We reiterate our position that an employer should not be liable if it meets the requirements in GINA 202(b)(2) or 202(b)(5) simply because it may be able to identify an employee based on the aggregate information. The statute does not contain the prohibition that EEOC has read into it. Moreover, reading the statute as broadly as EEOC is proposing would make employers reluctant to engage in important and otherwise lawful monitoring programs.

As with wellness programs, it is important to recognize that GINA section 206(c) renders provisions like GINA section 202(b)(5) surplus in circumstances where a HIPAA-covered entity provides the health or wellness service and there is no communication between such providers and the employer. *See* 42 U.S.C. §§ 2000ff-5(c).

*Section 1635.9 – Confidentiality*

We agree with the Commission that GINA section 206 does not require an employer to place genetic information about an employee or his or her family members that is publicly available into a confidential medical file and that disclosure of publicly available information by an employer (to the extent one can disclose what is already publicly available) does not constitute a violation of GINA.

*Section 1635.9(b) – Limitations on Disclosure*

We urge the Commission to make clear that employers are also permitted to make disclosures that are consistent with GINA sections 209(a)(1)-(7) and proposed 1635.9(b)(i)-(vii). *See* 42 U.S.C. §§ 2000ff-8(a)(1)-(7).

In addition, there are many instances where an employer did not request or require genetic information but the individual or third party has provided this information. The employer should be held to a standard that forces it to actively segregate such information that was inadvertently or passively received.

We also suggest the Commission note that the HIPAA medical privacy regulations have numerous exceptions to prohibitions on disclosure to address practical problems that may arise. Many of the exceptions under the medical privacy regulations illustrate rational instances in which a communication should not be considered a GINA violation. We are not asking EEOC to use the same definitions as HIPAA, but rather to look to the practical result of the HIPAA exemptions and not define certain communications as subject to GINA’s disclosure prohibition. Some examples might include:

- communication to a contractor performing relevant business functions, such as storing medical information on behalf of the employer or benefits administration (for example, where the employee has requested assistance in claims processing under the health plan);

- attorneys for purposes of litigation or legal assessment;
- when disclosure in response to warrants, subpoenas and administrative orders is permissible;
- communication pursuant to the employee's request;
- communication made in the context of sales or mergers of companies; and
- communication of information authorized by an individual.

*Section 1635.9(c) – Relationship to HIPAA Privacy Regulations*

As we note in our comments on section 1635.8(a), while employers may not request or require genetic information, GINA permits them to ask for information necessary to help manage job-related medical conditions or disabilities. GINA section 210 makes this clear. If part of such management is asking a doctor to evaluate those medical conditions or disabilities and provide advice with respect to the situation, that is not prohibited. That doctor is likely a HIPAA-covered entity and may obtain the necessary information, including genetic information. As the Commission notes, “nothing in section 1635.8 should be read as applying to or otherwise restricting the use or disclosure of genetic information that is protected health information subject to the HIPAA Privacy Rule.” 74 *Fed. Reg.* 9062 (March 2, 2009). Greater detail on this issue is set forth below in our comments on sections 1635.11(a) and (b).

*Sections 1635.11(a) and (b) – Relationship to Other Federal Laws*

As the Commission notes in the preamble, Congress intended to create a firewall between GINA Titles I and II. See 74 *Fed. Reg.* 9065 (March 2, 2009). GINA sections 206(c) and 209(a)(2)(B), 209(a) (7), and 209(c) ensure a complete firewall for activities of a group health plan from the provisions of Title II. The firewall provisions addressed in the proposed rule at 1635.11(a)(6), (b), and (d).

GINA section 206(c), which is addressed in the proposed regulation at 1635.11(d), provides a complete firewall for group health plans and health insurers. Group health plans' and insurers' use of health information, including genetic information, is fully subject to regulation under section 264(c) of the Health Insurance Portability and Accountability Act (HIPAA). Title II of GINA and the EEOC regulations do not apply to such information. There is no exception. The preamble contains an example concerning health care providers. That is one example, but group health plans and health insurers also are subject to regulation under 264(c) under HIPAA.

GINA section 209(b) and proposed section 1635.11(b) have additional language, which also creates a complete firewall. We support the proposed regulatory language in 1635.11(b) without any exception and note that any reading suggesting an incomplete firewall would be met with the full exclusion in GINA section 206(c).

In other words, section 206(c) and 209(b) operate as full exceptions from coverage of Title II of GINA. If an entity is subject to regulation within the provisions described under those sections, there is no circularity that allows such activities to be subject to Title II. The test is simply whether 206(c) or 209(b) apply. If they do, Title II of GINA will not apply. There is no further legal test that would suggest that in instances where those provisions apply there nonetheless would be a violation of Title II of GINA.

We emphasize this point because the following language from the preamble is somewhat confusing:

The Commission notes that the firewall does not immunize covered entities from liability for decisions and actions taken that violate Title II, including employment decisions based on health benefits, because such benefits are within the definition of compensation, terms, conditions, or privileges of employment. For example, an employer that fires an employee because of anticipated high health claims based on genetic information remains subject to liability under Title II. On the other hand, acts or omissions relating to health plan eligibility, benefits, or premiums, or a health plan's request for or collection of genetic information remain subject to enforcement under Title I exclusively.

74 *Fed. Reg.* 9065 (March 2, 2009).

While it is true that group health plans are not authorized to hire or fire employees of the employer who sponsors such a plan, it is very important that the EEOC does not allow claims of discrimination under Title II for activities that fall within the ambit of 206(c) or 209(b). The notion of a decision “based on genetic information” would have to have clear evidence as part of the process of firing that is separate and apart from activities of a group health plan or health insurers. We believe this is the Commission’s intent but think the language in the preamble to the final rule should clarify this point.

*Section 1635.12 – Medical Information That is Not Genetic Information*  
Please see our comments on Section 1635.3(g).

## **CONCLUSION**

We appreciate the opportunity to submit these comments. If we can be of further assistance on this matter, please do not hesitate to contact us.

Respectfully submitted,

### **Michael J. Eastman**

Executive Director, Labor Law Policy  
U.S. Chamber of Commerce  
1615 H Street NW  
Washington, DC 20062

### **Michael P. Aitken**

Director, Governmental Affairs  
Society for Human Resource Management  
1800 Duke Street  
Alexandria, VA 22314

### **Joshua A. Ulman**

Chief Government Relations Officer  
The College and University Professional  
Association for Human Resources  
Center Point Commons  
1811 Common Points Drive  
Knoxville, TN 37932

### **Michael T. Kolb**

Executive Director  
National Public Employer  
Labor Relations Association  
1012 South Coast Hwy, Suite M  
Oceanside, CA 92054

### **Robert A. Hirsch**

Director, Legal and Regulatory Affairs  
Associated Builders & Contractors, Inc.  
4250 North Fairfax Drive, 9<sup>th</sup> Floor  
Arlington, VA 22203

### **E. Neil Trautwein**

Vice President &  
Employee Benefits Policy Counsel  
National Retail Federation  
325 7th Street, NW, Suite 1100  
Washington, DC 20004

Of Counsel:

### **Joshua A. Ulman, Esq.**

Managing Principal  
Ulman Public Policy & Federal Relations

### **Nandan Kenkeremath, Esq.**

President,  
Leading Edge Policy & Strategy, LLC