

Submitted Via Federal eRulemaking Portal: <http://www.regulations.gov>

May 1, 2009

Stephen Llewellyn
Executive Officer
Executive Secretariat
U.S. Equal Employment Opportunity Commission
131 M Street, NE
Washington, DC 20507

Re: EEOC Regulations under the Genetic Information Nondiscrimination Act of 2008 – RIN 3046-AA84; Notice of Proposed Rulemaking, 74 Fed. Reg. 9056 (March 2, 2009).

Dear Mr. Llewellyn:

The Epilepsy Foundation is pleased to submit these comments to the U.S. Equal Employment Opportunity Commission regarding its proposed regulations that would implement Title II of the Genetic Information Nondiscrimination Act of 2008 (GINA). The proposed rules would prohibit the use of genetic information to discriminate in employment, and regulate how employers may obtain and store genetic information.

The Epilepsy Foundation, founded in 1968, is the national non-profit voluntary agency solely dedicated to the welfare of the more than three million people with epilepsy in the U.S. and their families. The organization works to ensure that people with seizures are able to participate in all life experiences; and prevent, control and cure epilepsy through services, education, advocacy and research. The Foundation has taken a leadership role in fighting discrimination affecting people with epilepsy since its founding. Given this role, and because there is a genetic component to epilepsy, the Foundation has a strong interest in the developing clear protections against improper disclosure of family medical history information related to epilepsy and against discrimination in employment on that basis.

We believe that the proposed regulations are quite comprehensive and would generally establish clear and reasonable standards that will ensure these goals are achieved. However, we have technical concerns regarding some of the rule's proposed exceptions to the prohibition on acquiring genetic information, which are discussed below.

Section 1635.8(b) sets out a list of exceptions to the general prohibition on acquiring genetic information contained in paragraph (a); these exceptions apply to genetic

information obtained inadvertently. The exception set forth in paragraph (b)(1)(iii) applies to the situation where “An individual provides genetic information as part of documentation to support a request for reasonable accommodation under Federal, State, or local law, as long as the covered entity’s request for such documentation is lawful.” The preamble discussion notes that this means that the request may not be overbroad, and refers to the Commission’s enforcement guidance on reasonable accommodations for “information on the type of medical information an employer may lawfully request in connection with a request for a reasonable accommodation.”

We are concerned that, because the enforcement guidance is only referenced in the regulatory preamble (and in any case does not create binding requirements under the ADA), it would not be binding on covered entities under GINA. Thus, the regulation itself would not provide clearly enforceable limits (or sufficient clarity) on the scope of the exception. In order to establish such limits, we recommend that the regulation itself be revised to incorporate relevant parts of the Commission’s ADA guidance (such as the material set forth in response to question 6). Accordingly, the regulation might be revised to read along the following lines:

An individual provides genetic information as part of documentation to support a request for reasonable accommodation under Federal, State, or local law, provided the covered entity does not seek documentation that is overbroad or unrelated to determining the existence of a disability and the necessity for an accommodation (such as a request for the individual’s complete medical records) and the covered entity’s request is otherwise lawful.

We have a similar concern regarding paragraph (b)(1)(v). This provision establishes an exception to the acquisition prohibition for genetic information provided to support a request for leave that is not governed by federal, state or local laws requiring leave, provided the documentation required to support the request complies with the ADA and other laws limiting access to medical information. Again, the preamble discussion states that information on the appropriate scope of inquiries in response to requests for leave is contained in EEOC enforcement guidance (on disability-related inquiries and medical examinations of employees). In order to establish clearly enforceable parameters to this exception, this provision might be revised to incorporate relevant language from EEOC enforcement guidance, in a fashion similar to our recommendation for paragraph (b)(1)(iii) above.

We recommend that similar revisions be incorporated into paragraph (b)(1)(iv), which establishes an exception to the prohibition where an employer requests medical information from an individual “as permitted by federal, state or local law,” and for paragraph (b)(1)(vi), which applies to health related inquiries, including one “about whether the individual has any current disease, disorder or pathological condition.” (Paragraph (b)(1)(vi) fails to even include the “as permitted by federal, state or local law”

language; at a minimum, that clarification should be made.) Such revisions for these provisions are also necessary to ensure that the standards are clear and enforceable.

Thanks very much for your consideration of our views.

Sincerely,

Gary Gross
Director
Jeanne A. Carpenter Epilepsy Legal Defense Fund
Epilepsy Foundation