Submitter Information

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General Comment

In implementing regulations, it will be important to address notice to consumers about non-discrimination. We suggest issuance of a model notice that has been tested for readability. People should receive notice both when they apply for insurance and when they are rejected for insurance about their rights under GINA and where to direct complaints if they believe they have been rejected or coverage for treatment has been excluded due to genetic information.

Though the law clearly states that plans are not to use information that they inadvertently receive from providers about family history and genetic testing in medical underwriting, to the extent possible, it would be easier for all concerned if health plan underwriters never received this information. Thus, it may be helpful for you to suggest record keeping systems for health plans and providers that keeps family history and genetic information separate from other medical records that are available to the health plan underwriters.
We look forward to reviewing draft regulations on how you will establish whether a condition is manifested or not, and on how you will coordinate enforcement with state insurance departments. These are important issues for consumers but we do not have a specific suggestion at this time.