New Rules Address Use of Genetic Information

BY MARY ELLEN SCHNEIDER

The federal government has issued new rules spelling out how it intends to police the use of genetic information by health plans.

The new regulations bar health insurers from increasing premiums or denying enrollment based on genetic information.

The regulations implement certain provisions in the Genetic Information Nondiscrimination Act (GINA), which was signed into law by President Bush in May 2008.

Beefing up consumer protections for genetic information should help accelerate progress in genetic testing and research, said Health and Human Services secretary Kathleen Sebelius.

"Consumer confidence in genetic testing can now grow and help researchers get a better handle on the genetic basis of diseases," Ms. Sebelius said in a statement.

In an interim final rule, federal officials provide details on how health plans can obtain and use genetic information. The regulation generally bars health plans from increasing premiums based on genetic information. They also cannot require, or even request, that individuals or family members undergo genetic testing. And health plans cannot request, require, or purchase genetic information at any time for underwriting purposes, or prior to or in connection with enrollment.

Although the rule bars insurers from charging its members more based on genetic information, it doesn't limit them from doing so because of the manifestation of a disease. However, a health plan can't use the manifestation of a disease in one of its members as genetic information for a family member and raise their premiums, according to the interim final rule.

The rule does allow plans to request limited genetic information if it's necessary to determine the "medical appropriateness" of a certain treatment.

Plans also can request that individuals participate in research where genetic testing will be conducted. However, none of the genetic information collected during that research can be used for underwriting purposes.

The interim final rule goes into effect 60 days after publication in the Federal Register. ■

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