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Circular Letter 97-4

TO: All Insurance Industry Representatives, Insurance Trade Associations and Interested Parties

FROM: John A. Greene

Director of Insurance

DATE: July 14, 1997

RE: Genetic Testing Form Mandated by House Bill 2144 and A.R.S. §20448.02

I am pleased to announce that the Department has created a consent form to be used by insurers and other companies that require insureds or prospective insureds to take a genetic test in connection with the effectuation of life or disability insurance coverage. This form, required by a new law enacted during the recently completed legislative session, prescribes the information that must be given to consumers and the form of consent that must be executed when a company requires the administration of a genetic test. Laws 1997, Ch. 229 (House Bill 2144).

In the development of this form, the Department took note of concerns that the new law could be read to prevent companies from conducting the types of tests routinely used to underwrite life or health insurance. For instance, questions have been raised about whether the new law will prevent routine blood, urine, saliva or other diagnostic tests from being administered because these tests also could be used to perform genetic tests. Questions have also been raised about the impact of the new law on the administration of HIV tests.

Tests for HIV continue to be governed by A.R.S. § 20-448.01 rather than the new law. Further, the new law does not prohibit companies from conducting tests designed to enable the company to assess the health of an insured or prospective insured even though the same test (or test sample) could also

be used to identify or diagnose a genetic condition. In addition, the new law does not prevent a company from asking health or family history questions as part of the process of effectuating coverage. When the company requires that a test be performed specifically to determine whether a person has a genetic condition, the new law applies and requires that the consent form be used. Further, the provisions of A.R.S. § 20-448.01(A) also apply to a genetic test administered by others, if a company uses the results of that test to effectuate insurance coverage.

The Department's efforts also focused upon the confidentiality of the information gathered as a result of the administration of a genetic test. The law declares that "[t]he results of a genetic test performed pursuant to this subsection ***are privileged and confidential*** and ***may not be released*** to any party ***without the expressed consent*** of the subject of the test." A.R.S. §20448.02(A) (emphasis added). This provision applies only to tests administered under this new law. While this provision does not apply to the results obtained from genetic tests performed in other contexts that a company may obtain from other sources, other laws address how a company must handle this information. See A.R.S. §§ 20-2101 through 20-2120.

The Department recognizes that insureds and prospective insureds may raise questions about how companies will guard their privacy interests related to genetic testing, as required by the Legislature. At the same time, the Department recognizes that the process of securing consent may pose some administrative difficulties for a company when making business decisions about the insurance obligations the company may assume or has assumed. For instance, the securing of reinsurance on a book of business often requires that the reinsurer have access to files, including files that may contain the results of a genetic test. In any event, information that is privileged and confidential in the hands of a company retains this character when disclosed to those to whom disclosure has been expressly authorized.

Companies may ask consumers to consent to the situational release of genetic test results without necessarily identifying the specific recipient of that confidential information. However, a company must provide consumers with sufficient information about the class of persons or entities to whom the results of genetic tests will be given to secure "expressed consent." The legislature's decision to require "expressed consent" compels this result, because for the consent to be "expressed", the consent must be "stated or declared in direct terms; set forth in words; not left to inference or implication." *Blacks Law Dictionary*, p. 521 (5th ed. 1979). When requesting that a consumer provide express consent beyond that provided in the form that accompanies this circular letter, companies should look to the exceptions noted by the Legislature in A.R.S. § 20-2113 for guidance.

The Department also considered whether to include information in the consent form to advise consumers that they may seek counseling before or after they have received the results of a genetic test. Because the statute does not address the issue of counseling, the consent form does not address this topic. However, the statute directing the Department to develop the consent form does not prevent the exercise of professional responsibility by those who require or administer genetic tests. Health care professionals are well versed and experienced in advising their patients of medical issues that become evident following the administration of diagnostic tests, including genetic tests. Likewise, companies, who have an obligation to deal fairly with their policyholders, should consider how best to deliver information gained from a genetic test in a manner that permits the information to be understood.

In addition, the Department considered drafting the consent form to include information about the two standards contained in subsections E and F of A.R.S. §20448, as amended by House Bill 2144. These laws establish differing standards that impact the manner in which companies may use the

identification of a genetic condition, depending upon whether the insurance product at issue is life or disability insurance and depending upon the precise manner in which a company identifies the existence of a genetic condition. In concluding that information of this sort did not need to be included in the consent form, the Department determined that these points in the law have more applicability to a company's market practices rather than to securing informed consent. Under the law, the legislature took clear steps to ensure that consumers would know that a particular test would be used to perform a genetic test. The legislature did not prescribe that the consent alert consumers to every provision of the law potentially implicated by the administration or analysis of the results of a genetic test. In large measure, these points have already been addressed in other portions of the law, including the Insurance Information and Privacy Protections Act with provisions that require companies to advise consumers of adverse determinations. A.R.S. §§202101 through 20-2120. Thus, the consent form does not describe every prohibition against unfair discrimination that applies to a company's use of genetic tests or the presence of a genetic condition in effectuating insurance contracts. The absence of this information from the consent form does not relieve a company of its duty to ensure that consumers receive accurate information about the terms of any policy issued or to be issued. A.R.S. §20443.

The consent form contains blanks for each company to identify itself on the forms that it uses. In addition, a company may add any other identifying marks to these forms. However, the forms must contain the information contained in this form to be in compliance with the new law.

A company that uses the genetic testing consent form attached to this circular letter will not have to file the consent form with the Department for approval. A company that chooses to add to the consent form attached to this circular letter, including to obtain additional authorizations to disclose the results of genetic testing, must file the form with the Department for approval.

[To view the form, click here](#)

NOTICE AND CONSENT FORM FOR GENETIC TESTING

(insurer name)

(name of person being tested)

(insurer address)

(name of person giving consent, if different)

Unless specifically authorized or required by law, you cannot be required to take a genetic test without your specific, written, informed, prior consent or the consent of a person authorized to consent for you.

To evaluate your eligibility for insurance coverage, _____ (insurer name) _____ requests that you consent to the following genetic test(s) to be performed for the following reason(s):

Test name or type: _____

Test name or type: _____

Reason(s) for test: _____

Reason(s) for test: _____

Genetic Test means an analysis of an individual's DNA, gene products or chromosomes that indicates a propensity for or susceptibility to illness, disease, impairment or other disorders, whether physical or mental or that demonstrates genetic or chromosomal damage due to environmental factors, or carrier status for disease or disorder. A blood, saliva, or other test does not constitute a genetic test unless performed specifically to analyze your DNA, gene products or chromosomes.

The results of this genetic test are privileged and confidential and may not be released to any party without your expressed consent.

CONSENT TO GENETIC TEST AND

CONSENT TO RELEASE OF GENETIC TEST RESULTS

I have read and understand this Notice and Consent Form. I voluntarily consent for myself or the proposed insured to the genetic test(s) for the reason(s) specified above and understand that I have a right to request and receive a copy of this form. I give my expressed consent to _____ (insurer name)'s _____ release of the results of the genetic test(s): **(a)** to its affiliates, employees, contractors, reinsurers, or assigns, **(b)** in response to a court or administrative order, subpoena or warrant, or **(c)** to an insurance regulatory authority. A photocopy of this form will be as valid as the original.

___ I want to receive the results of my genetic test.

___ I authorize the **additional** release of the results of my genetic test to the person named below:

Signature of Person to be
Tested or Parent/Guardian

Name (your **additional** release authorization)

Address

Date