

## Chapter Nine

### Genetic Discrimination



#### A. Background

“AD has been established as a familial disorder ...,” in the sense that “numerous epidemiological studies ... have documented an increased risk for AD in the close relatives of individuals with a diagnosis of AD” (Bird 1994). Beyond this association, which does not necessarily prove a genetic basis for the disease, investigation of families with extensive, multi-generational AD has shown that mutations in certain genes can cause early-onset AD (Lendon 1997; St. George-Hyslop 2000; Tanzi and Parson 2000). In the small population at risk for early-onset AD, testing for these genes, if coupled with appropriate genetic counseling, may well yield useful information (Post 1997; St. George-Hyslop 2000).

With respect to late-onset AD, a variant of APOE, a gene that codes for a protein related to blood cholesterol, is associated with an increased risk among Caucasians.<sup>1</sup> The extent to which this variant, called APOE4, elevates risk depends on whether an individual has inherited one or two copies of the gene. A recent study found that the presence of a single APOE4 variant was associated with a 2.73-fold increase in risk (Evans, Bennett, Wilson et al. 2003). Two copies of the gene, with an incidence of approximately 2 percent of the general population, are associated with a ten-fold increase in risk (Evans, Skrzynia, and Burke 2001).<sup>2</sup>

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Nevertheless, although “this increased risk is significant, inheritance of an E4 variant of the APOE gene is neither necessary nor sufficient to cause [AD]. Other factors influence disease incidence, including other ‘risk’ genes and environmental factors” (New York State Task Force on Life and the Law 2000, at 18). Consequently, the use of APOE genotyping is not standard practice and remains controversial. Many urge caution: “A positive test is an imprecise measure of risk and could result in anxiety, stigmatization, or discrimination. The principle of avoiding harm suggests that currently such testing would generally be unethical because no effective prevention is available” (Evans, Skrzynia, and Burke 2001; Nussbaum and Ellis 2003). Some scientists, however, urge patients and physicians to “use this genetic information to develop strategies to reduce the risk of developing AD [and] make appropriate plans for the emergence of this disastrous condition ...” (Ashford and Mortimer 2002). Indeed, survey results suggest that, for a variety of reasons, many people are interested in genetic susceptibility testing (Neumann, Hammitt, Mueller et al. 2001; Roberts, LaRusse, Katzen et al. 2003).

## **B. Current Law**

Maryland law prohibits genetic discrimination in the provision of health insurance and in employment. With respect to health insurance or health benefits coverage, the Insurance Code generally prohibits the use of genetic testing<sup>3</sup> and of genetic information<sup>4</sup> in underwriting, renewal, or rate-setting decisions.<sup>5</sup> This protection, like comparable federal law,<sup>6</sup> is limited to health coverage; the prohibition explicitly “does not apply to life insurance policies, annuity contracts, long-term care insurance policies, or disability insurance policies.”<sup>7</sup>

With respect to employment, an employer may not refuse to hire, discharge, or otherwise discriminate

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against someone on the basis of genetic information about the individual or the individual's refusal to submit to, or provide the results of, a genetic test.<sup>8</sup> Employers are also forbidden to request or require genetic testing or genetic information as a condition of hiring or for determining benefits.<sup>9</sup>

### **C. Preventing Discrimination in Long-Term Care Insurance**

The explicit exclusion of long-term care insurance from the genetic discrimination provision of the Insurance Code raises a significant policy question. Nothing in Maryland law forbids an insurer from denying an individual long-term care coverage because of genetic information about the individual.

We do not know whether any insurers now obtain or rely on genetic information about AD risk as part of the underwriting of long-term care insurance. Even if none now does, however, given the accelerating rate at which knowledge of genetic risk is accumulating, it is only a matter of time until they do. If, as we suggest, sound public policy would bar the use of genetic testing or information in underwriting or rate decisions about long-term care insurance, the right time to act is now, to prevent harmful consequences rather than await them.

Maryland already has a clear public policy in favor of long-term insurance. This policy is manifest in the tax credit for eligible long-term care premiums.<sup>10</sup> The General Assembly's expectation, presumably, is that greater reliance on long-term insurance will reduce the burden of nursing home costs on the Medicaid program.<sup>11</sup> Moreover, Maryland law explicitly requires coverage of AD.<sup>12</sup> This public policy would be undermined if coverage could be denied on the basis of predictive genetic information about AD risk. In addition, allowing long-term care insurers to require genetic testing for AD or use genetic information about

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AD risk would interfere with what ought to be the prerogative of individuals to decide for themselves whether to obtain information about increased risk for this disease (Rothstein 2001). For comparable reasons, various professional groups have called for a prohibition on the use of predictive genetic tests to determine eligibility for long-term care insurance (Post 1997). Other states have enacted comparable protections.<sup>13</sup>

**RECOMMENDATION 9-1:** The General Assembly should extend the protections in § 27-909 of the Insurance Code to long-term care insurance.

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## Endnotes

1. It is not clear whether APOE4 is a lesser risk factor for African Americans (Evans, Bennett, Wilson et al. 2003; Froehlich, Bogardus, and Inouye 2001; Green, Cupples, Go et al. 2002).

2. Conversely, inheritance of a different variant, APOE2, may be protective (Evans, Bennett, Wilson et al. 2001).

3. A genetic test is "a laboratory test of human chromosomes, genes, or gene products that is used to identify the presence or absence of inherited or congenital alterations in genetic material that are associated with disease or illness." Insurance Article § 27-909(a)(5), Maryland Code. Gene products are RNA and proteins. § 27-909(a)(2).

4. Genetic information is information about "chromosomes, genes, gene products, or inherited characteristics ... obtained for diagnostic an therapeutic purposes . . . at a time when the

individual to whom the information relates is asymptomatic for the disease.” § 27-909(a)(3)(i).

5. § 27-909(c).

6. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) bars employer-sponsored group health plans from considering risk-related genetic information alone as a “preexisting condition” subject to a one-year exclusion from coverage. 42 U.S.C. § 300gg(b)(1)(B). Because of the preemptive effect of the Employee Retirement Income Security Act, 29 U.S.C. § 1144(b)(2)(B), only HIPAA, not State law, applies to these employer-sponsored plans.

7. § 27-909(b). This subsection originally did not identify long-term care insurance in the exclusion. When § 27-909 was substantially revised by Chapter 51 of the Laws of Maryland 1999, the exclusion was amended to mention long-term care insurance specifically.

8. Article 49B, § 16(a)(1) and (2), Maryland Code (as amended by Chapter 12 of the Laws of Maryland 2001). The terms “genetic information” and “genetic testing” have the same meaning as in the Insurance Code.

9. Article 49B, § 16(a)(3).

10. Tax-General Article, § 10-718.

11. Starting in December 2005, the Comptroller is to submit an annual report about the tax credit that is to include “the savings under the State’s Medical Assistance Program as a result of additional individuals being covered by long-term care insurance as a result of the credit.” Tax-General Article, § 10-718(e)(2).

12. Insurance Code, § 18-111. The text of this provision is as follows: “Except for coverage excluded under a preexisting condition provision, long-term insurance shall provide coverage for [AD] or other senile dementia disorders without any condition, limitation, or reduction of coverage not applicable to coverage for other diseases or illnesses.”

13. Colo. Rev. Stat. Ann. § 10-3-1104.7(3)(b); Vt. Stat. Ann. Tit. 18, § 9334.