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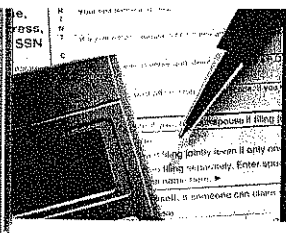
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It's All in the Genes

By Michael Gilfix



FEATURE: ESTATE PLANNING & TAXATION

By **Michael Gilfix**

It's All in the Genes

As scientific testing reveals some of our bodies' predispositions—how should we plan for our future?

It can be exciting! Splice that “high-cholesterol gene” out of there. Create the perfect child. She’ll be the athletic genius you always wanted to be. Get rid of that weak chin, that spontaneous giggle that wells up in the most inopportune circumstances. Find that gene and snip it out!

While these opportunities exist in science fiction, we’re not quite there in the real world, but we’re getting close. (See “Advances in Genetic Testing,” p. 19.)

Developments in our ability to use and understand genetic information and the passage of new legislation have profound legal and estate-planning implications. These advances present equally challenging questions for employers, health care providers and insurers. For example, what if an insurer doesn’t want to provide coverage to someone who has a genetic predisposition to a certain disease?

In response to these issues, the legislature passed the Genetic Information Nondiscrimination Act (GINA), which then-President George W. Bush signed into law on May 21, 2008.¹ While GINA is incomplete and effectively nascent in its evolution, it’s a vitally important piece of the legislative landscape as we look at medical and genetic testing. It profoundly affects millions of families who have or may have genetically based medical conditions. It also reminds us that there’s a wealth of information about genetics that can affect the recommendations we make to our estate-planning clients.

State Legislation

Discrimination based on genetic testing isn’t a new

area of concern. Over the past 20 years, most states have enacted legislation that prohibits different types of discrimination based on genetic information. By 2008, no fewer than 47 states had enacted legislation that prohibited genetic discrimination in the area of health insurance,² and approximately 35 states had enacted legislation prohibiting genetic discrimination in the field of employment.³

For example, California passed its own version of the Genetic Information Nondiscrimination Act, which took effect on Jan. 1, 2012.⁴ It’s significantly broader than federal GINA legislation, in that it prohibits discrimination based on genetic information in such areas as housing, lending, employment, education and public accommodations.

Generally speaking, health insurance legislation at the state level prohibits the use of predictive genetic information when an individual applies for health insurance. In the context of employer-sponsored group health plans, federal law preempts and controls regulation of such plans. Employers are generally prohibited from using genetic tests as a precondition for employment or using such information in personnel decisions.⁵

GINA Effective Dates

Title I of GINA, which relates to health insurance, took effect on May 21, 2010. Title II, which relates to employment discrimination, took effect on Nov. 21, 2009. The Equal Employment Opportunity Commission (EEOC) issued final regulations on Nov. 9, 2010, which took effect on Jan. 10, 2011.⁶

What’s Prohibited

GINA prohibits discrimination based on genetic information in the areas of health coverage, insurance and employment. Along with the provisions in the Health



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Advances in Genetic Testing

Stanford Medical School neurologists predict we'll soon be able to determine to a 90 percent certainty whether an individual will develop Alzheimer's disease

I participated in a conference at Stanford Medical School on "Predicting Alzheimer's Disease" in September of 2011. My fellow speakers included Hank Greely, Stanford Law professor and director, Center for Law and the Biosciences, and Drs. Frank M. Longo and Michael D. Greicius of the Stanford Department of Neurology and Neurological Sciences. From the neurologists, we learned how remarkably close we are to the refinement of genetic, neurologic and other testing that will enable us to determine to a 90 percent certainty whether an individual will develop Alzheimer's disease.

At least three companies, including 23andMe of Mountain View, Calif., will analyze an individual's DNA. Based on that analysis, some predictive information emerges. Dr. Francis Collins, current director of the National Institutes of Health in Bethesda, Md. and prior director of the Human Genome Project, reportedly obtained such information and learned of a predisposition to diabetes. As a result, he changed his diet and his exercise regime, illustrating the positive uses of such analysis.

— Michael Gilfix

Insurance Portability and Accountability Act of 1996,⁷ GINA prohibits health insurers and planned administrators from requiring genetic information from an applicant or his family members.⁸ When insurers have such information, they can't use it to determine coverage or rates for coverage. In the context of employment, employers with 15 or more employees are prohibited from using such information when making decisions about hiring, discharging, promoting or otherwise affecting terms of an individual's employment.

This means that insurers and employers can't ask questions about family medical history on applications or before making decisions about insurance coverage or hiring, respectively. For example, an insurance applica-

tion may not ask about the cause of death or particular medical conditions of an applicant's parents or grandparents. Also, an insurer can't require an individual to undergo genetic testing as a precondition of coverage. They're not, however, prohibited from obtaining medical history information for positive purposes, such as a referral to a supportive program designed to address or ameliorate medical conditions to which an applicant may be predisposed.

"Genetic information" includes information derived from a person's genetic tests, genetic tests of family members up to the fourth degree, any manifestation of a disorder in a family member or information about an individual's—or an individual's family member's—participation in research that includes genetic testing or screening.⁹

"Genetic tests" refer specifically to tests that assess or determine genotypes, mutations or chromosomal changes.¹⁰

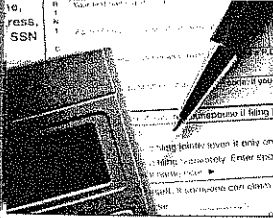
Enforcement responsibility is delegated to the Department of Health and Human Services, the Department of Labor and the Department of Treasury, with regard to insurance. The EEOC has responsibility for employment discrimination matters. There's a private right of action, particularly with regard to employment claims.

When there's a finding of intentional unlawful employment practices, courts may order reinstatement or hiring of employees with or without back pay. Courts also have the authority to enjoin employers from engaging in such unlawful practices and may award the prevailing party attorneys' fees and costs.

What's Allowed

This legislation, which is the product of years of deliberations and hearings, is limited. While it applies to health insurance and employment, it doesn't prohibit the use of such information in the context of life insurance, disability insurance or long-term care (LTC) insurance.

GINA doesn't prohibit insurance or employment decisions based on genetics when a medical condition has already manifested or appeared. Put differently,



GINA's protections only apply to individuals who haven't yet exhibited symptoms of a condition that might be accurately predicted by genetic information.¹¹

Once a disease or other condition has manifested, state insurance legislation applies. Generally, health insurers are allowed to refuse renewal of health insurance or to increase premiums in light of adverse health developments.

In fact, it can be very difficult to separate the two. At what point has a genetically predicted disease "manifested itself?" To date, no court has issued a decision addressing this difficult question.

Perhaps most importantly, GINA's protections don't apply to life insurance, disability insurance or LTC

Genetic information that affects life expectancy is of obvious relevance to life insurance underwriting decisions.

insurance. While it's unclear the extent to which insurers obtain or rely on such information, the temptation is obvious. If genetic testing reveals or can reveal that an individual will develop Alzheimer's disease within the next 10 years, an LTC insurance provider isn't likely to ignore such directly relevant information if it's legal to use it. Genetic information that affects life expectancy is of obvious relevance to life insurance underwriting decisions. This could take stranger-owned life insurance approaches to even greater heights. While insurers may not review or have access to genetic information affecting life expectancy prognostications, nothing in the law prevents the life insurance investment industry—those who fund or purchase life insurance policies—from vigorously seeking such information. Rate of return calculations could, thereby, be reviewed with increased reliability.

Planning Considerations

If a 60-year-old can take a genetic test to determine the likelihood of developing Alzheimer's disease within the next 10 or 15 years, he might be sorely tempted to do so. A positive test would be life-changing on countless levels.

Many people would terminate or minimize employment. Travel and other sources of enjoyment may take on an elevated priority. Diet and exercise regimens could change. Personal relationships would presumably be more valued and come into sharper focus.

A future with Alzheimer's disease, most poignantly, suggests a need for more comprehensive and costly LTC services. Such care may be provided in the home, an assisted living facility or a skilled nursing facility. The cost can range from hundreds of dollars per month for home care to over \$12,000 per month for skilled nursing care in some communities. Nationally, the average cost of skilled nursing care in 2012 was \$6,752.50¹² per month.

Medicaid eligibility for LTC. Asset acquisition, management and divestment would, inevitably, be viewed differently. If dementia and its resulting care needs are in an individual's future, he might seriously consider conveying all or most assets out of his name, so that Medicaid eligibility will be available to pay the cost of otherwise expensive LTC. If assets are transferred more than 60 months before a nursing home resident applies for Medicaid coverage, such transfers have no negative impact on eligibility. The 5-year look-back period in the Deficit Reduction Act of 2005 can easily be accommodated.¹³

Such planning steps may be viewed as overly aggressive and premature. If so, at minimum, individuals should modify their durable power of attorney to include language specifically authorizing the attorney in fact to transfer assets and take other protective steps if LTC services become necessary.

LTC insurance. If an individual with new genetic information already has LTC insurance, he's fortunate. This is particularly true if the policy is comprehensive and reliable. If an LTC insurance application is being submitted, all medical records—including documentation of Alzheimer's disease or other diagnoses—can be examined and considered.

Remember: GINA doesn't prohibit reliance on genetic information in the area of LTC insurance. Individuals should carefully examine state legislation in such circumstances.

If genetic testing has been done by a company that has privacy guarantees, such information may remain confidential. The existence of such information, nevertheless, presents numerous questions and challenges.

Veteran's benefits, including aid and attendance. A veteran or the spouse of a veteran can partially recover the cost of home care and assisted living through

the Veteran's Administration Aid and Attendance program.¹⁴ Veterans must first satisfy certain asset eligibility criteria. Generally speaking, an individual can have no more than \$80,000 in countable assets to qualify. There are, however, no penalties if the individual transfers assets to satisfy this requirement.

While this suggests that no precipitous action steps must be taken, planners must keep in mind the eligibility penalty that will be imposed if transfers were made and an individual subsequently applies for Medicaid. Even a modest transfer could create a punishing problem for an individual in need of skilled nursing care.¹⁵


Estate tax planning. An individual with a potentially taxable estate will more vigorously pursue leveraged transfers and other sophisticated tax avoidance planning to eliminate estate tax exposure if he learns that his life expectancy is abbreviated or compromised. He may be strongly tempted to transfer assets in 2012, when he can transfer up to \$5.12 million out of his estate without incurring gift or estate tax liability. With the expiration of the Bush tax cuts as of Jan. 1, 2013, millions of dollars that would otherwise be exposed to estate tax can be protected.

Special needs planning. Special needs planning is appropriate when an individual is disabled and expected to qualify for government benefits on the basis of need. If genetic information indicates that a child is likely to develop a disabling physiological condition or mental limitation, the parents can implement special needs planning earlier and with more protective impact. Parents would be more likely to integrate a special needs trust (SNT) into their estate plan when such information is available and deemed reliable.

Parents would be more likely to obtain life insurance to ensure substantial funding of an SNT. They would take care to avoid inclusion of life insurance proceeds in their taxable estates by using an irrevocable life insurance trust in their planning.

Parents could advise grandparents and other relatives of such proclivities and coordinate their estate plans so that the disabled child is comprehensively protected. They would, for example, direct any bequest to the SNT established for the disabled child, rather than having that bequest go directly to the child.

With many diagnoses, a genetic link has already been conclusively established. This is the case with bipolar disorder. If parents or grandparents experienced this disorder, proactive and protective planning is logically

indicated. Such planning is very challenging, as parents always want to be hopeful and avoid stigmatizing a child who may never manifest symptoms. 

Endnotes

1. P.L. 110-233, 122 Stat. 881, codified at 42 U.S.C. 2000ff *et seq.*
2. See 75 F.R. 68912.
3. See "Establishing Federal Protections Against Genetic Discrimination," *American College of Physicians Policy Monograph* (2008) at p. 3.
4. *Ibid.*
5. See California Senate Bill No. 559.
6. See Health Insurance Portability and Accountability Act of 1996 (HIPAA); see also Executive Order 13145, which was executed and issued by then-President Bill Clinton in 2000. The executive order prohibited the use of genetic information as a basis for discrimination in federal employment.
7. Pub.L. 104-191, 110 Stat. 1936.
8. For example, Title I of HIPAA prohibits discrimination in individual eligibility, benefits or premiums based on any health factor, including genetics. Furthermore, HIPAA prevents a plan or issuer from imposing a preexisting condition exclusion based solely on genetic information. The Genetic Information Nondiscrimination Act (GINA) prohibits plans and issuers from requesting or requiring an individual to undergo a genetic test and restricts the collection of genetic information. See U.S. Department of Labor, FAQs on the Genetic Information Nondiscrimination Act, www.dol.gov/ebsa/faqs/faq-GINA.html.
9. 42 U.S.C. Section 2000ff(4).
10. Examples of protected tests are tests for breast cancer or colon cancer that flow from mutations, classification of genetic properties when therapy is being developed for an existing tumor, testing for Huntington's disease mutations and screening to determine if an individual is a carrier for such diseases as cystic fibrosis, sickle cell anemia, spinal muscular atrophy and fragile-X syndrome. See Kathy L. Hudson, M.K. Hotohan and Francis S. Collins, "Keeping Pace With the Times—the Genetic Information Nondiscrimination Act of 2008," *New England Journal of Medicine*, June 19, 2008, at pp. 2661-2663.
11. GINA allows adverse actions based on "genetic information about a manifested disease, disorder, or pathologic condition." See Title II of GINA, Section 1635.3(g); see also 29 C.F.R. 2590.701-3(b)(6)(i) ("if an individual is diagnosed with a condition, even if the condition relates to genetic information, the plan may impose a preexisting condition exclusion with respect to the condition, subject to the other limitations of this section").
12. See Genworth Cost of Care Survey 2012, www.genworth.com.
13. See Deficit Reduction Act of 2005 (Pub.L. 109-171) Sections 6011 and 6016.
14. See 38 C.F.R. Sections 3.271-277, "Regulations Applicable to the Improved Pension Program Which Became Effective January, 1979."
15. See Michael Gilfix and Bernard A. Krooks, "Throw Momma from the Train," *Trusts & Estates* (March 2006) at p. 36.