

# Genetic Testing: An Issue Whose Time Has Come?

by Henri Bersoux

Man's predestination—his lack of control over his own future—has always been cause for thought. But advances in genetic research may one day enable man to exert some control over his destiny. In the meantime, this research has opened a Pandora's box of troubling questions, many of which will have to be addressed by insurers.

Today, scientists are developing genetic tests that indicate what diseases may—or will—develop in a person's lifetime. And some day, researchers agree, doctors may apply that knowledge to correct genetic defects, slowing or stopping the onset of certain ailments.

More than any other single medical discovery, the science of genetics is sure to affect the insurance business.

Like the search for a cure for AIDS, genetic research is yielding a wealth of knowledge that will undoubtedly lead to great advances in medicine. But a debate is likely to emerge on societal guidelines to govern the use of that knowledge. The controversy that is sure to follow, according to many who are familiar with the issue, will dwarf that caused by the AIDS crisis.

Certainly, all agree that how the insurance industry reacts to developments in genetic research will largely guide how the industry is affected.

Today actuaries speak with great care of the potential use of genetic testing in underwriting, expressing the concern that thus far there is not enough data upon which to base a clear policy.

But while some in the industry would apparently prefer to reserve comment until more is

known, the media is paying increasing attention to this emerging issue. And virtually every article published to date mentions implications for insurers. Some articles even discuss these implications in detail.

Despite the fact that genetic science is in only its infancy, journalists inevitably seem to report on the worst-case scenarios that they assume are inevitable. One recent article in the *Washington Post*, for example, used one of two hypothetical scenarios dubbed "notes from the future" to show how an insurance company would use a minor genetic defect to reject an otherwise healthy applicant.

The article described a 31-year-old male, a swimmer and avid racquetball player, with no previous hospitalizations. In the process of applying for life insurance, this fictitious character is said to have been given a sophisticated DNA test. That test reveals a molecular misprint that more than triples his risk of getting small-cell lung cancer by age 45. The article implies that the insurer rejects the applicant on that basis alone.

John Booth, the ACLI's vice president and chief actuary, is quick to point out that, "A tripling of the risk of death from a relatively rare event such as small-cell lung cancer would not result in anything near a tripling of overall mortality. The applicant would, more than likely, not only be accepted for life insurance but perhaps even qualify for the standard rate."

The impact that genetic testing could have on underwriting is significant. In his report to the Genetic Testing Committee of the ACLI medical section, Mark E. Battista, M.D., vice president and

medical director of UNUM Life Insurance Company, discusses a number of issues. "The rapid growth of genetic technology," writes Dr. Battista, "will clearly have an impact on insurers regardless of whether they incorporate genetic testing into underwriting. . . . If insurers do not proceed with genetic testing," he adds, "adverse selection will become a significant issue."

And that may initially be the crux of the matter, as far as underwriters are concerned.

A 1985 *Business Week*-Harris Poll revealed that 75 percent of Americans feel insurance companies would not be justified in declining to insure people whose genetic tests indicate they are likely to come down with a fatal disease. Yet the same poll showed that fully 50 percent would go ahead and take the tests for their own knowledge. The result might be a public in possession of critical knowledge legally kept from life underwriters.

But adverse selection is not the only concern. As this wealth of new-found information reaches the public, the sale of life and health insurance may be dramatically affected in other ways, as well. A person whose genetic makeup is deemed excellent, for example, may be less inclined to purchase anything but accident insurance. "People buy insurance as a safeguard against untimely death," says Ian Rolland, chairman of the board and CEO of The Lincoln National Life Insurance Company and chairman of the Society of Actuaries. "Test results that reduce or eliminate some of the uncertainties of life could change the nature of our business."

Mr. Rolland, who reported on genetic testing to the ACLI medical section in June, outlined an unfavorable scenario for the emergence of genetic testing.

If insurers rush into genetic testing without considering all of its ramifications, said Mr. Rolland, they might well add fuel to the fire that the press has begun to build. Some of the dangers the industry might face are:

- that some insurers might use the first genetic tests that come

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along without adequate investigation into their predictive value.

- that some will start to use genetic tests before establishing strict guidelines on confidentiality.

- that genetic tests might be used before counseling issues are resolved.

- that the premature use of genetic tests by insurers might force tight government controls over the entire underwriting process.

"AIDS," says Mr. Rolland, "focused the public's attention on risk classification and our need to test. Genetic testing will take over where AIDS leaves off."

Robert J. Pokorski, M.D., is second vice president and medical director at Lincoln National, and chairman of the ACLI medical section's Genetic Testing Committee. He points out that much of the public's concern about the possible use of genetic tests in underwriting stems from its lack of knowledge about how private voluntary insurance works. The basic arguments of the advocacy groups that will oppose testing will be very familiar.

In a report to the medical section entitled "The Potential Role of Genetic Testing in Risk Classification," Dr. Pokorski outlines some of the factors that underlie public skepticism. They include:

- beliefs that it is unfair to classify risks based on factors that people cannot control.

- concerns that insurers will use genetic tests to disqualify large numbers of people from affordable insurance coverage.

- concerns that insurers will be unable to deal satisfactorily with issues such as confidentiality and informed consent.

- ethical concerns that genetic tests for any reason other than tightly restricted medical purposes will be used to restrict human rights.

According to Dr. Pokorski, it will be at least ten more years before genetic predisposition tests will be available for screening large numbers of people. And, therefore, it will probably be ten years as well before doctors can apply the knowledge derived from genetic testing to

preventive care and medicine. Indeed, it may be at least several decades before remedies are found for most genetic defects.

And while this may seem like a long period during which to work out the moral and ethical problems associated with genetic science, or even the extent to which the insurance industry might make use of the information, it represents a window of vulnerability. Until the public can see the knowledge provided by testing applied to therapy, an early poll indicates, it is likely not to agree to its use in underwriting. "We must," says Dr. Pokorski, "communicate clearly that we support first and foremost the scientific investigation of genetic testing from a diagnostic standpoint.

"Because unfamiliarity breeds fear, the lack of information available to the public is certainly our gravest challenge," Dr. Pokorski continues. "If brought to the public's fullest attention in the wrong framework, the potential use of genetic testing for anything but therapy could well generate the same kind of hysteria witnessed at the outset of the AIDS crisis."

If it were not for adverse selection, the problem would indeed be less critical. In the case of AIDS, for example, testing is vital to the industry, and both the insurer and the applicant now have access to the information. While adverse selection is undoubtedly still taking place, the industry has some ability to control it.

Genetic testing, however, involves scrutiny of ailments that have long been taken into consideration in mortality and morbidity tables. There will be no rash of premature deaths as a result of new diseases. The insurance industry will not start from behind on this particular issue, providing it gains access to testing at the same time as the public. And that, according to Otto Meletzke, senior counsel at the ACLI, will largely be governed by how responsibly insurers are perceived to be handling the issue.

Each time scientists uncover specific information about a gene or set of genes, different issues arise out of the specific implications of a disease or predisposition that they transmit.

As genetic testing becomes more widely used in daily medicine, the potential for adverse selection will grow. In the *Washington Post* story referred to earlier, reporter Rick Weiss correctly recognized the adverse selection problem and added a twist. He wrote that, "... underwriters are frightened by the prospect of individuals performing genetic analyses on themselves—and keeping the results secret. . . . Home testing for DNA markers could amplify the effect of the industry's arch nemesis—'adverse selection.'"

It is, of course, impossible to assure the public that batteries of genetic tests will never be used in underwriting. Just as extensive blood tests are now relatively inexpensive, it may some day be cost-effective to undertake multiple genetic tests. Said Dr. Pokorski, "By the year 2000, genetic testing will probably become standard practice within the medical community."

The industry is being drawn into a debate that has far-reaching implications. Life insurers stress the importance of educating the industry on the issue. They say that the industry must position itself as a responsible interlocutor during what promises to be a long and bumpy road into the 1990s.

Mr. Rolland, addressing the ACLI's Board of Directors in September, said, "Our best hope here is to establish our own guidelines for using this technology. We must remember that such (genetic) tests must satisfy a higher standard before they can be used to screen insurance applicants.

"My suggestion," he added, "is that we must do our best to manage this issue very carefully. We should study it; we should make our policy very carefully and very slowly and only when we are in possession of the facts." ☉