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## UNDERWRITERS' CORNER

## Genetic Information: Is It the Same or Different from Other Medical Information?

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**Submitted by:** Richard L. Bergstrom

By Donald C. Chambers, M.D.

### Question(s)

Do you think that genetic information is different, and if so, should insurers handle it differently from other medical information?

### Answer(s)

Assuming that you are referring specifically to inherited DNA-based test information predictive of future disease, I have no doubt that this sort of genetic information is far more sensitive than most other medical information. I say "most" because AIDS—and perhaps drug and alcohol addiction and mental illness information—are equally sensitive. My beliefs with respect to the second part of your question are less certain.

The political insight editorial, "Genetic Testing Takes Center Stage," in the August issue of *Best's Review* quoted an ACLI spokesperson as saying that "our view is that genetic information is just like a routine medical test." The ACLI has consistently maintained that genetic information is no different than other medical information. They frequently make the case that all medical information is in some way genetic; thus it's impossible to make a distinction between medical information based on genetic characteristics.

In a recently published American Cancer Society publication, *Cancer and Genetics*, the case is made in chapter one that genetic information does differ from other medical information. The following reasons are cited. DNA information is:

- *Personal.* What could be more individual than one's DNA?
- *Predictive.* Unlike most medical tests, genetic tests give healthy peo-

ple information about potential future risk—an eerie and possibly scary prospect.

- *Powerful.* The information has the power to change the course of lives, plans, and behaviors.
- *Private.* It's still not certain how, and from whom, to shield genetic information. Who will have access to these records? Employers? Insurance carriers? Potential marital partners?
- *Pedigree-Sensitive.* The information affects not just your patients, but their relatives. What is your obligation to them?
- *Permanent.* Until gene therapy can make a lasting change in one's genome, the results are here to stay.
- *Prejudicial.* Even the whiff of potential disease could create discrimination or stigma.

Those who choose to make no distinctions between genetic information and other medical information may regard the above as contrived, but this list collectively does a good job of expressing why I, and the majority of people, do in fact believe that genetic information is especially sensitive and thus is different.

To distinguish genetic test information (again, inherited DNA-based test information predictive of future disease) from most other medical information has seemed helpful to me for practical reasons alone. Today a vast majority of the public would almost certainly agree that information about a genetic mutation that is likely to lead to future life-threatening disease, and that has been inherited by someone from their mother and/or father—a mutation that brothers, sisters, sons, and daughters may also possess—is not "just like" blood pressure or cholesterol. If one believes that "perception is

reality," then to argue that genetic information is like other medical information seems futile.

Having said that, there is rationale and value in distinguishing genetic-test information from most other medical information, and respecting genetic information for its high degree of sensitivity, does it necessarily follow that one must therefore adopt special information-handling practices to safeguard genetic privacy? The fact that insurers have done this for HIV data would suggest that this can and should be done. When one begins to carve out subsets of medical information for special handling, however, it's obviously hard to know where to stop. I've slowly come around to thinking—along with many others—that it makes no sense to adopt special information-handling practices for a myriad of medical information categories. A single set of sound handling practices should be capable of protecting all personal information, be that information highly sensitive in nature, such as genetic-test information, or routine, such as total serum cholesterol.

So, is genetic test information different? Should it be handled differently? I would say that the appropriate way for insurers to respond to those questions is to say, "Yes, genetic-test information is different and is not like most other medical information; but the fact is that the insurers treat all personal information, medical and otherwise, in a respectful and highly confidential manner. Insurers have always done an outstanding job of protecting personal information, and we are committed to doing an equally good job in the future, whether we are dealing with genetic or any other type of personal information."

For more information, contact: Donald C. Chambers, M.D., Senior Vice President and Chief Medical Director, Lincoln National Corp., Fort Wayne, Indiana.

Phone: 219-455-3922

Fax: 219-455-6650

E-Mail: dcchambers@lnc.com