

By Cecil D. Bykerk

Barring abuse, genetic testing could be a useful tool for doctors and insurers alike. But misguided legislation could result in unfortunate unintended consequences.

When Genetic Testing Collides

THE HUMAN GENOME PROJECT has been in newspaper headlines and on television news shows around the country in recent months. The focus of the attention has been on the vast new knowledge and insights into our human bodies and our ancestry that genetic research affords us. In addition, future medical and health care possibilities are almost unimaginable and seem limitless.

But this news is almost as scary as it is exciting. Do we really want to know what's wrong with us, or could go wrong with us in the future? Perhaps, if it's something that can be altered or prevented. But what if it can't be fixed?

Where is the dividing line between being sick and having certain attributes that suggest future sickness? Can people with a given genetic flaw be considered healthy? Or were they sick the moment they were born?

While much has been discovered about genes, most genetic testing is focused on discovering flawed genes, those genes that have the potential to cause health issues for us or for our children. The treatment or cure for these flaws in most cases hasn't yet been developed, though it's expected treatments will be developed in the future.

And where will the resources for these come from? Most people assume health insurance should pay for it, since it seems to pay for almost all other treatments. If insurance policies are to pay for treatment, the companies managing these policies will need information, if for no other reason than to pay claims.

But even before that, should companies be allowed to re-

quest information during the enrollment (underwriting) process? Should they be allowed to require applicants to take certain genetic tests before their application will be considered?

And what about individual privacy? If they gain the knowledge, will insurers guard that information carefully, or will they, if they can, sell that information to interested parties?

Will people applying for coverage exercise antiselection? And how will antiselection affect the cost of coverage for what are sure to be expensive treatments?

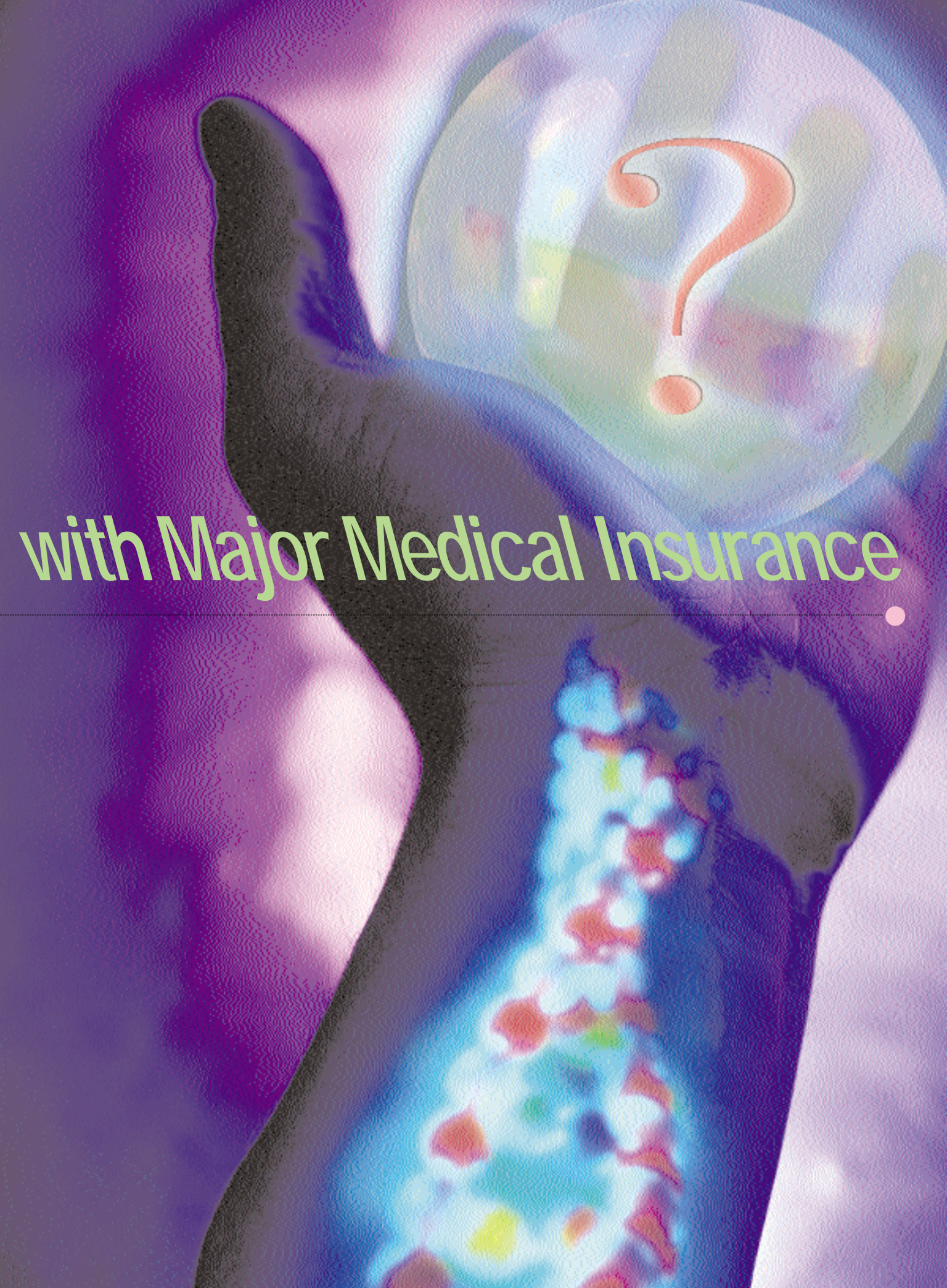
In the years ahead, Congress will be asked to deal with these and other issues surrounding genetic testing. To do so, legislators will have to understand insurance in general; the differences between major medical insurance and other types of insurance; and the importance of underwriting.

The Underwriting Paradox

We in the industry know what insurance is, what it's for, and how it works. But much of the general public misunderstands insurance and what it's really meant to do. Even less is understood about the underwriting process. As we try to deal with, and respond to, the outcries of alarm regarding genetic testing, we must first try to understand where the general public is coming from.

Insurance is a sharing or pooling of risk. The individuals who want to share the risk of health insurance should all have an equal likelihood of getting sick. The ones who get sick can be said to be getting a return on their money, the healthy peo-

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with Major Medical Insurance



ple will not. In fact, some will get a return that is many times what they paid into the pool while others, who never need health care, will get nothing back.

At one level, most people can easily understand this principle. But there is still a feeling that if they get nothing or even very little back, they've been cheated. (It doesn't matter that being cheated in this case also means being healthy.) Also, the public doesn't distinguish very well between voluntary insurance, mandatory or semi-mandatory insurance, and social insurance. Or perhaps people do not fundamentally agree with how the various forms of insurance should be delivered.

Underwriting is the process of classifying individuals into the appropriate risk-sharing pool. It differs depending on whether the insurance is sold on an individual or group basis. If some individuals in a pool have an advantage over the others, they have antiselected against that pool, i.e., the other policyholders.

Life insurance is underwritten, too.

Most people have some life insurance over and above the \$255 they get from Social Security. In many cases, an employer provides life insurance as an employee benefit. But many people voluntarily purchase additional individual coverage directly from an insurance company. And in most cases, some form of underwriting is performed.

If the face amount of the coverage is small, the underwriting might be minimal. But as the face amount increases—the more the insured pool represented by the insurance company has at risk—the intensity of the underwriting increases. (Annuities require very little underwriting because an untimely death would disadvantage the purchaser rather than the company.) In general, underwriting focuses both on whether the individual is healthy today and on any risk factors that might suggest the individual's health in the future. What is important to the topic of major medical is that the general public has not yet gotten to the point where it perceives that purchasing life insurance should be a right or that the government should provide large sums of it. The same holds true for other forms of insurance, such as disability income and long-term care.

For example, if a homeowner were able to purchase fire insurance on his already burning house, he would have antiselected against the other homeowners in the pool. The general public seems to understand and agree that this would be unacceptable. Insurance is designed to protect against a future event, an event both insured and insurer usually hope will never happen. It's not designed to compensate someone who didn't plan well and wants to avoid the consequences.

Underwriting protects everybody's opportunity to buy affordable insurance. During the underwriting process, the insurance company will look at the house, its condition, the shin-

gles on the roof, the foundation, the exterior construction, etc. And of course, it will make sure that the house isn't burning, or sinking, or otherwise damaged.

Another example: Consider an applicant for a bank loan. During the underwriting process, the bank will investigate the applicant's credit history, determine whether he has declared bankruptcy in the past, and decide whether he has the ability to pay back the loan in the future.

In this case, underwriting presents the same paradox: Those who need a loan the most can't get one, and those who don't need one can get a loan easily. Almost all people accept that process and understand why the bank needs to underwrite the applicant even though that applicant may need the loan to purchase a home or a car or some other essential item.

But when it comes to major medical insurance, the general public does not have the same appreciation for the underwriting process. People have come to

believe that everyone has a right to health insurance. Both liberals and conservatives believe this, differing only in the way in which this right is delivered.

Liberals would have the federal government provide the coverage through national health insurance or a national health care program. In this case, underwriting would be completely moot and the issue of genetic information or testing wouldn't enter the picture other than as a benefit covered under the plan.

Conservatives would prefer to keep government out of the delivery process. They look to a private mechanism for providing health insurance, but they still believe that access to coverage should be guaranteed. While many would provide that guarantee through some mechanism such as high-risk pools, many in the middle of the spectrum feel that the right to have coverage or health care overrides the normal insurance pooling requirements.

Because they don't fully understand the pooling process or appreciate the underwriting process, these people are ready and willing to ban the use of genetic testing in underwriting. They don't trust insurers to keep the information confidential, even though insurers have an excellent track record in guarding other medical information. And they consider it an invasion of privacy.

On the other hand, most people will expect major medical insurers to pay for having genetic tests performed in the clinical setting, and for any gene treatment whenever it becomes available. Obviously, insurers will have a difficult time paying claims for tests and treatment if they're not even allowed to determine if the tests are necessary. Including genetic testing and treatment in an already very expensive insurance product will only put it further out of reach of those who can't afford it now, and will make it unaffordable for some who currently have the coverage.

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What Constitutes a Genetic Test?

But is this all necessary? Genetic information generally will tell us much more about possible future outcomes (is the house safe and well built?) than it tells us about current conditions (is it on fire?). The public and the legislators are focused on major medical because of its unique position as a supposed entitlement. For many who feel this way, any underwriting process for major medical is already perceived as inappropriate—inappropriate because it may stop people from obtaining coverage *just when they really need it*.

Let's examine current major medical underwriting in those states that still allow it. Essentially, such underwriting is a process of determining whether a person is sick—right now. We know that everyone will get sick in the future. So the question is, is the applicant sick now?

Some of the facts that would be sought include height and weight ratio, currently diagnosed diseases or conditions, any prescriptions currently being used, and blood pressure levels, as well as various measures that are derived through the analysis of blood, including cholesterol levels, liver functions, kidney functions, triglycerides, and diabetes. All of these indicators are accepted in the clinical process of determining whether someone is sick.

What's different about major medical insurance that causes

this focus on current health? The average major medical policy duration is around 3 years, plus or minus a year. Thus, the future perspective that genetic testing might provide for the insurer isn't very important. Such testing is very expensive and, at this time, tends to be fairly specific (narrow). It's not economical for an insurer to pay for tests that provide such limited immediate information. Even family history, which some consider genetic information, is not used in the underwriting of major medical insurance.

So why are so many people exercised over the issue of major medical and genetic testing? I believe it's the attitude that access to health insurance is a right that gets in the way of looking at genetic testing rationally. It's the public's misunderstanding of insurers and underwriting that makes genetic testing such an emotional issue.

But if major medical insurers aren't really interested in genetic information and wouldn't use it even if they had it, then why are they so concerned about the bills that are being advanced in Congress?

They're concerned for several reasons. First, the definitions of genetic testing being advanced are overly broad and can easily be interpreted to sweep in many underwriting tools that are accepted by the majority of the public today. Some of the proposed definitions would interpret tools such as height, weight,

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and blood pressure—tools doctors and hospitals use every day—as genetic tests. Such a definition would effectively remove them from the insurer's underwriting toolbox.

The proponents of these various bills are, in most cases, quick to point out that these types of tools are not what they intend to prohibit. But the court system is notorious for deciding in favor of plaintiffs when an insurer is on the other end of an issue. If this were to happen, it would fall in the category of unintended consequences. If the major medical insurer's tools are even more limited than what they are today, more antiselection will take place, resulting in even higher premiums and more uninsured.

Finally, any definition written into law today will most likely be applied when the next effort comes about in extending the limitations to long-term care, disability income, or life insurance. It's only a matter of time. Some special interest groups are already demanding that extension.

Blazing a Trail

It's instructive to examine how some of the other types of insurance differ from major medical.

Disability income insurance has a much longer term than major medical. It's heavily occupation-driven and not generally dependent on genetics, though there could be some genetic issues related to certain industries and jobs. Thus, genetic an-

tiselection would most likely be greater than with major medical but less than with long-term care insurance.

Long-term care insurance is also longer term than major medical and probably disability income. Occupation is taken out of the picture, but heredity plays a significant role in an individual's longevity and may indicate possible outcomes of aging. The potential for antiselection is increased tremendously. And it may not be long before society begins to view long-term care as a right, too.

So whether it wants to or not, major medical is blazing the trail through the genetic testing jungle. As future scientific discoveries and changes are made, unintended consequences may occur as a result of legislation passed today that could not anticipate the quickly evolving science. Extending any definition of genetic testing to other forms of insurance in which the one-sided knowledge of genetic information is more important than it is to major medical must be weighed very carefully. Any definition that is written into law today will most likely be applied to future legislation that uses the terms 'genetic test' and 'genetic information.'

Will any law prevent the concerns and the fears that plague the citizens now with respect to genetic testing? HIPAA has been interpreted to require guaranteed renewal of all individual major medical policies, but we continue to hear stories of people being singled out and having their premiums increased or their policies cancelled. Follow-ups have yet to find any of these cases to be true, but the stories and the fears and the concerns persist. What can we do to solve that problem regarding genetic testing? Passing overly broad legislation is probably not the solution.

Despite all of the above, legislation will no doubt move forward. If it does, it will have to consider

- Consistency between the processes and standards for protecting the confidentiality of genetic information and the privacy requirements of all patient medical information;
- Scope of the genetic test and genetic information definitions;
- Safe harbor provisions to define what is *not* a genetic test or genetic information;
- Prohibitions against genetic testing requirements for health insurance applicants;
- Limitations on the use of genetic information.

As we ponder this problem, even bigger problems loom on the horizon. Where is the dividing line between being sick and having certain attributes that suggest future sickness? Are those with a given genetic flaw healthy, or are they sick the moment that they are born? Additionally, the issue of whether limiting legislation is passed with respect to the use of genetic testing in the underwriting process will pale in significance compared with the impact that the costs of reimbursing for genetic testing and genetic treatment will have on major medical as we know it today. ●

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