

A LINE ON LIFE

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Would You Really Want to Know Your Future? *

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Knowing the future seems impossible. However, if you could know some things with certainty about your future, would you want to know?

The federal government has a Human Genome Project to try to identify the estimated 80,000 genes that make up human DNA — and the millions of variations of these genes. It seems to be running almost two years ahead of its 2005 target for completion. With this genetic information, we hope to understand individual genetic differences. It could lead to revolutionary ways to diagnose, treat and prevent thousands of biologically caused disorders — including psychiatric ones. How will people react emotionally to this knowledge? What if you were to know years in advance that you are at risk for a deadly or disabling illness?

In September of 1998, Dr. Francis Collins, director of the National Genome Research Institute, addressed the American Psychological Association (APA) convention. He indicated that genetics research affects psychology in two ways. First, it will help us understand the biological basis for human behaviors. Second, psychologists need to help individuals who may struggle with the decision to be tested for various diseases. However, before this, in 1996, the APA had already created an advisory council on genetics to deal with these problems.

Although some people welcome this genetic information, it is not always the case. Suppose you are a physician, whose patient has been diagnosed with genetic indicators for breast cancer. However, she refuses to tell her sisters that they have a 50% chance of carrying the same gene. Should you notify her sisters and violate her confidentiality?

A similar problem exists with **Huntington's disease** — a degenerative disorder of the nervous system. With a parent who suffers the disease, they have a 50% chance of inheriting the deadly gene. In surveys, these people indicate that want to take a test to find out if they have the defective gene. However, researchers at John Hopkins University School of Medicine have found that they rarely seek out testing. Upon questioning, they indicate that they are worried about their emotional reactions to the results. Negative results would lead to instant feelings of relief. On the other hand, positive test results have been found to lead to major depression.

One assumption about genetic screening is that the high-risk people will take steps to minimize their problem. Recent research of the National Cancer Institute studied women who had tested positive for **BRCA1** — a genetic marker of high risk for **breast cancer**.

Those who had the marker were not more likely to get regular mammograms than those without the marker. Knowing you have the risk does not necessarily mean that you will take steps to minimize it.

There are other family problems related to genetic testing that psychologists need to explore. Parents may need counseling about whether to tell their children that they be genetically predisposed for a serious disease. One spouse might feel anger toward another for carrying a "*bad gene*" that leads to a disorder in their child.

Psychologist Andrea Farkas Patenaude — research director of the Dana-Farber Cancer Institute's pediatric oncology division — indicates that one of the most controversial issues is the **duty to inform**. If patients test positive for a genetic risk, they may not want to tell other family members. This means that the family members will not have the knowledge, so they can take preventative measures to reduce their risks.

Even physicians are split on this problem. One group — the American Society of Human Genetics — indicates that doctors have the privilege of disclosing genetic test results to family members. However, this has two conditions.

- Family members must be facing risks of serious harm.
- There must be preventative measures they can take to reduce their risks.

In contrast, the International Bioethics Committee of the United Nations Educational, Scientific and Cultural Organization that genetic information should be confidential from third parties. To this Patenaude asks, "*The question is, are other family members third parties, or are they patients?*"

The question of third parties also brings up the problem of insurance carriers. Essentially, insurance carriers are betting that you do *not* get a disease or some other tragic occurrence. If they find out that any person is high risk for any disorder, that person would be considered a "*bad bet*." They would not be insured, or if they were insured, the payments would be excessive. How could you guarantee confidentiality of genetic testing, so the insurance company would not find out and cancel your insurance?

If you could tell what disorders were in your future, would you really want to know?

Knowing this, would you really want to know your future? However, at least now, in some cases, you will have a choice. It may be a difficult one, but it is still *your* choice.

* Adapted from Scott Sleek's "How will genetic testing affect us emotionally?" [*APA Monitor*](#), October, 1998, page 35.