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ABOUT GENES

Born With A Pre-Existing Condition

By Robert Pollack

WHILE NO SPECIFIC passage in the Declaration of Independence, the Bill of Rights or the Constitution guarantees total privacy, our laws nevertheless grant us the right to draw many lines neither government nor strangers may cross without our permission. Today we stand on the edge of losing a cornerstone of our right to privacy — not to a foreign power or a home-grown tyrant, but to a mixed bag of medical technologists, insurance companies and molecular biologists. By Independence Day 2001 there is a good chance that the very center of our private lives, the genes that created us, will no longer be private property.

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Here's how it might happen.

At the moment of conception when sperm and egg unite, all the genetic information necessary to form a new person is present in the one-celled embryo. Each of us has two versions of each human gene. This unique combination remains the same through fetal development, birth, childhood, maturity and old age. Until about 10 years ago, a person's particular version of a gene was a closed book; today, we know of about a thousand genes that have one or more versions which contribute to human disease. Further, the rate at which new genes are discovered, decoded and made available for easy detection is increasing rapidly.

This has given all interested parties — doctors, lawyers, insurance companies, employers, politicians and, most of all, the rest of us who want healthy, happy lives — a new, DNA-based ability to predict the onset of a partially or wholly inherited illness. Today, we can even predict whether an individual has a propensity to develop some cancers.

Now that the particular versions of many different genes can be easily identified, we all have a shared responsibility to decide how to use this prophetic power. We already know that not all the knowledge we can gain from our genes is information we will always want to have. Huntington's disease, for example, can be predicted by DNA before symptoms ever develop; however, there is little one can do but wait for the inevitable appearance of the disease.

But the ability to prophesy can be an essential part of family planning. Prenatal DNA diagnosis coupled with abortion provides a rational way to avoid bearing a child with a life-threatening in-

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herited disease. As molecular diagnostic techniques are put into play to uncover the genes carried by a fetus, all interested parties must agree which versions of any genes are to be considered normal and which may be taken as markers of future disease; otherwise, we run the risk of using this technology simply to select babies by design.

Taken together, the questions raised by our new ability to predict the future are as painful as they are obvious: Do we want to keep our genes a mystery, or do we want to know what we will die of, and when? Do we want anyone else to know this about ourselves or about our children? These and many other issues at the boundaries of medicine and basic science have defined a new sort of privacy right, one that all other privacy rights are dependent upon: the ability to control the information contained in one's own genes. Unless we are prepared to have our future health known to anyone who might today know our credit rating, now is the time to protect our genes from prying eyes.

Today, insurance companies may choose whether to offer health coverage on the basis of a person's current medical history. Outright refusal or exorbitant fees often follow the discovery of any "pre-existing condition," most notoriously the presence of HIV, even in the absence of symptoms. It takes only a small stretch of the imagination to see pre-existing conditions extended to any gene that might give rise to an illness in later life: In that case, all of us would have a good chance of being found uninsurable, no matter what the state of our current health.

Health-care reform has preoccupied Congress and the president, but there's been little, if any, discussion of genetic privacy. Both law and politics move slowly; the technology is moving much faster than either has recognized. As a result, issues of genetic privacy present us with unexpected and nasty surprises. We can now gather data on an individual's genome that are the equivalent of nuclear fuel: Once obtained, it cannot be safely buried or forgotten, but must be constantly guarded lest it damage the lives of future generations. If the health-care debate doesn't tackle the issue of genetic privacy now, molecular biology's contribution to medicine will continue to put us at increasing risk of losing — in the name of a better future — our hopes for that future and our freedom to enjoy it.