THE LAST WORD/

THE GENOME INFORMATION
PRIVACY ACT

by Gordon J. Edlin

Breakthroughs in genetic diagnoses through restriction fragment length polymorphism (RFLP) or linkage analyses in many instances already far exceed our ability to use such information wisely. The legality of compiling an individual's "genetic dossier" has yet to be determined, but is an issue that must be confronted. Without informed debate today, the following scenario may be closer to reality than we care to imagine:

"Tension was high in the conference room today as testimony on the Genome Information Privacy (GIP) Act continued before a Select Senate Committee. As you know, the GIP Act would guarantee to every citizen the right to conceal information about his or her genetic defects from almost everyone.

"Genetic privacy is being supported by a curious coalition of the political left and right. The American Civil Liberties Union (ACLU) has actively supported GIP based on Fourth Amendment protection against illegal searches and seizures. The ACLU argues that a person's genes are the same as personal property and cannot be investigated without probable cause. The National Rifle Association (NRA) has also lobbied intensively for the GIP. The gun lobby believes that the right to bear any and all kinds of genes is akin to the right to bear arms, and that both are guaranteed under the Constitution.

"Arrayed against these well-organized supporters of GIP is a coalition of political moderates and powerful business interests who urge that the bill be defeated.

"At today's session, Dr. Y, a high-ranking government scientist, finally agreed to testify before the committee—on the condition that his identity not be revealed.

Dr. Y: All of us in this room are affected by genetic abnormalities—I no less than most. Yet my so-called "defects" do not prevent me from making a useful contribution to our society.

Thus it is with a heavy heart that I appear before you today. I must confess that my present emotional state is due to a gene called *cry*. Fortunately, genetic counselors assure me that my *cry* alleles are not fully expressed, so I need not worry about breaking down before your committee. The *cry* gene, however, does cause my lips to quiver and my voice to crack occasionally—for which I apologize.

Although you cannot see me behind this screen, I also must tell you that I am quite overweight. As you undoubtedly know, this is caused by the *fat* gene first isolated in Iowa. In my case, despite dietary precautions, this gene seems to be expressed at a high level. As a result I am doomed to a life of obesity.

My wagers on various sports events and secret trips to Las Vegas are being investigated by the Justice Department. But these peccadillos aren't my fault. I carry a dominant *bet* gene that causes me to wager compulsively.

My personal physician has recommended that I continue to indulge these minor vices: diverting the *bet* gene's expression thus significantly reduces the chance that I will bet on the results of my own experiments. As I lack the prerequisite intent, the criminal charges against me simply are not justified.

My well-documented drinking problem—acknowledged before being appointed to my present post—is due to the *lkr* gene that requires me to maintain a reasonable level of alcohol in my blood to ensure normal brain function. Interestingly, the *lkr* gene is closely linked to the gene that generates a craving for potatoes (*crv*). It is my hope that by screening persons for the *crv* gene we soon will be able to identify potential alcoholics.

I would also like to admit that during my college years I smoked illegal grass-like substances. This was not by choice—my *pot* gene made me do it. I am glad to say that expression of this gene decreases with age as silencer sites become activated, so I am no longer troubled by the urge to smoke anything except cigarettes which, of course, is due to the *nic* gene.

The committee should know, too, that my attacks of depression and occasional hallucinations are caused by the *krz* gene that I carry. I count myself fortunate, however, that I do not have the *mad* gene; the National Institute of Mental Disorders has shown that *mad* can lead to premature senility and early retirement. I am controlling my *krz* gene by a combination of psychoactive drugs and head massage; my mental health is good.

Recent studies from the Human Genome Sequencing Project have shown that three genes in a row produce a common array of compulsive nervous habits: a tendency to wink (*tic*), a tendency to act spontaneously (*tac*), and a tendency to tap one's foot (*toe*). Luckily, you can't see me behind this screen. I have all three genes.

Finally, I want to state emphatically before this committee and the American public that I did not become infected by the money gene (\$\$\$) (reported in *Bio/Technology* 6:252, Mar. '88) when I accidentally stuck myself with a needle containing a sample of Donald Trump's DNA. In any case, I was probing Mr. Trump's DNA for the success gene (*suc*) at the time I reported the wound and filed for compensation.

I hope my testimony convinces members of Congress that GIP is unnecessary legislation. I also want to take this opportunity to encourage every citizen to report his or her defective genes as honestly and completely as I have done when the FBI genetic investigator knocks on your door.

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