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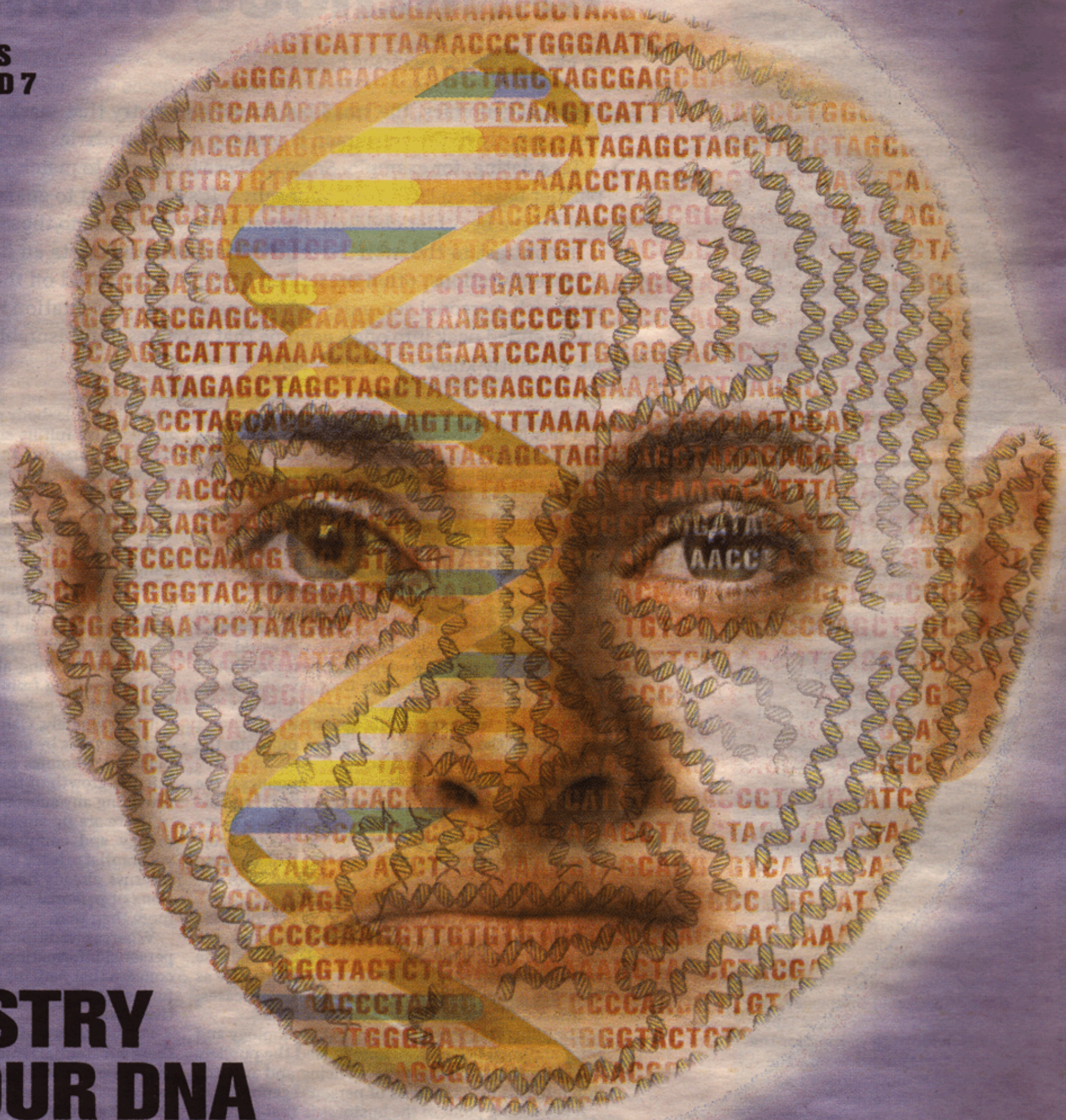

# THE INDUSTRY OF YOUR DNA

*Illustration by John Blanchard / The Chronicle*

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PERSONAL GENOMICS

# THE HUMAN BLUEPRINT: DANGEROUS SECRETS

BY DOV GREENBAUM AND MARK GERSTEIN

Personal genomics, the small but growing industry that markets a broad range of DNA tests directly to the consumer, is pushing new boundaries every day.

Take dating, for example. Some of these firms aim to match you with your optimal life partner based on DNA from your saliva. It's an attempt to guarantee physical chemistry, and maybe healthier children, by matching your genes to those of your potential mate.

In contrast to the more established industry that tests an individual for single gene disease mutations, often prescribed by physicians based on their understanding of genetic risk, personal genomics (which has much representation in the Bay Area) is a more open-ended peek into one's genome that provides immeasurably more information than we currently know what to do with.

And that is a problem.

A relatively unregulated personal genomics industry, focusing on providing the public with complex genomic data that is to all intents and purposes more revealing than closely guarded medical records, and encouraging them to share it with their friends, raises many nontrivial issues.

The real concern facing consumers of personal genomics lies in the potential for a total loss of privacy, not just for the consumers themselves, but their immediate relatives who share much of the same DNA and who have not provided the informed consent to divulge their genotype to the world.

Although we do not understand even a subset of the genetic influences on our lives, eventually we will; but by then it will be too late to retract the genomic data that many of us uploaded.

In short, the technology is going out into the world fast — perhaps too fast.

The underlying science of personal genomics is the result of a confluence of many computational and biological successes. Nobel-Prize-winning DNA sequencing technologies gave way to the genome project, a decadelong government endeavor that gave us a representative sample of the entire human DNA sequence — the fundamental blueprint of life.

Subsequently, there has been an effort to annotate the genome and catalog the millions of sequence variations between individuals. Though the variations are mostly benign, they are instructive as they are often correlated with genetic diseases, health conditions or physical characteristics.

The plunging costs of sequencing technology and computational power have now turned the publicly funded success of genome sequencing and annotation into this new business of personal genomics.

A key selling point of the business is that an analysis of one's unique combination of genetic variations can be used to reveal or predict substantial medical information. Moreover, just as throughout history humans have been intrigued by their mirrored reflections, portraits, photographs and more recently whole-body diagnostic scans, personal genomics also fulfills an innate human desire to understand ourselves and our place in the world.

There are serious applications of the technology, including personalized medicine: a not-so futuristic reality where a doctor will be able to prescribe and dose according to our particular genotype, effectively providing for more efficacious and less dangerous pharmaceuticals with fewer side effects.

Moreover, personal genomics not only promises to reveal useful and pertinent medical information about ourselves, but also gives individuals a chance to participate in groundbreaking research.

Notwithstanding all the potential positive outcomes resulting from personal genomics, we must be wary of the potential threat to our privacy.

Unfortunately, California's recent efforts to protect the public by imposing strong regulation on the personal genomics industry will only serve to stymie the growth of this important resource without providing any substantive privacy protections.

There are no simple solutions. As both biotechnology and computer technology push forward, substantial privacy issues will continue to arise. The Internet already has begun to change our perceptions of personal space. Personal genomics will do more than that.

Whereas traditionally privacy meant control over personal information, personal genomics raises the concern that perhaps you ought not control that information that also impinges on your close relatives' privacy.

Further laws and regulations will not easily solve these substantial issues. Instead, these recent genomic advances will require society to fundamentally re-evaluate and redefine our current standards of medical confidentiality and privacy.

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