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Dena S. Davis
Cleveland State University, d.davis@csuohio.edu

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PINK SLIP INTRODUCTION

DENA S. DAVIS¹

Is there a pink slip in your genes? In this cleverly worded phrase, Paul Miller adroitly captures the fears of millions of Americans as we ponder whether the genetic revolution bodes us well or ill. The Human Genome Project (HGP), which completed its first phase in 2000, succeeded in mapping the entire human genome, a breathtaking accomplishment. Scientists promise that, in the future, genetic knowledge will enable us to fight cancer, treat hitherto intractable genetic diseases, create drugs perfectly calibrated to the needs of the individual recipient, come up with vaccines to fight new epidemics, and other wonders. But meanwhile, while we await these promised miracles, the primary accomplishments of genetic research have been to *identify*, rather than to treat. We can identify Tay-Sachs carriers, but we cannot treat Tay-Sachs. We know that some women are at increased risk of breast and ovarian cancer because of their genetic make-up, but we can offer them little more than increased surveillance and prophylactic surgery. We increasingly accept the notion that almost every health condition has a genetic component, but treatments and prophylaxis remain virtually unchanged.

What has changed, however, is the degree of worry and concern that people feel about the uses to which their genetic information can be put. When the HGP began, a number of pundits were convinced that the “future knowledge” that genetic information can deliver to consumers and insurers alike would completely undermine the practice of private health insurance, and send our current system crashing to the ground. Needless to say, that has not happened; but with 42 million Americans currently without health insurance, and with insurance tightly entwined with employment, many people fear that genetic information will be used by employers and insurers to discriminate against those who appear to present higher risks.

For most people, the HGP appears like an abstract and distant enterprise. It is not, hard, however, to imagine scenarios that are anything but abstract and distant.

My mother died of Huntington Disease. Will any one want to hire me, knowing there is a fifty percent risk that I will have HD as well? My spouse and I carry sickle cell trait. Although we are healthy, we risk having children with sickle cell disease. Can we get health insurance? If we have jobs with insurance, can we afford to move, knowing that a new employer might not want to add potentially expensive employees to the group insurance pool? My sister was just diagnosed with breast cancer. I'd like to have my own genetic risk analyzed, but I am afraid that, if the news is bad, my insurer will somehow get hold of it and cancel my coverage just when I need it most. I'd like to take part in a new research project focusing on genetic diseases associated with my ethnic group

¹Professor of Law at Cleveland-Marshall College of Law, Cleveland State University. J.D., University of Virginia; Ph.D., University of Iowa. Professor Davis is widely published in the fields of bioethics and religious studies.

because I hope that in the long run it would benefit a lot of people, but I worry that my private information will get into the wrong hands.

In the December 2001 conference at Cleveland-Marshall College of Law, titled *Is There a Pink Slip in Your Genes? Genetic Discrimination in Employment and Health Insurance*, we tried to grapple with these questions. Thoughtful speakers addressed topics such as our current state of genetic knowledge; whether genetic discrimination exists; whether litigation, legislation, healthcare reform or some mixture of these approaches offers the best promise of combating discrimination; whether the Americans with Disabilities Act is a strong shield against such discrimination, and the very meaning of “disability” in this new age of genetic knowledge. We are grateful to all who participated, and in this symposium issue of *The Journal of Law and Health*, we invite our readers to share the fruits of this endeavor.